

**The Experiences, Perceptions and  
Meaning of Recovery for Swazi  
women living with *Sifo Sengcondvo*  
'Schizophrenia'**

**Siphiwe Carol Nxumalo - Ngubane  
University of Salford, UK  
School of Nursing, Midwifery Social Work & Social  
Science**

**Thesis  
Submitted in Partial fulfilment for the requirements  
of the degree of Doctor of Philosophy**

**November 2016**

## Acknowledgements

I would like to express my earnest appreciations to several people, without whom this project could have not come to fruition. Firstly, my supervisors Dr Susan McAndrew, and Dr Elizabeth Collier. Thanks for your patience, encouragement and support throughout this journey. For the passionate constructive review of my work, this has led to my intellectual development; and the birth of this project, which will hopefully improve the quality of lives for people living with schizophrenia in Swaziland. Therefore, I want you to know that you have engraved a mark, not only in my life, but to the multitude who will benefit from the outcome of this project.

I am so grateful for my colleagues, for reading and constructively criticising my work, this has given me insight into perspectives I would not have realised had it not been for your input. I would like to express my heartfelt gratitude to the informants who shared their stories with me, and your courage and trust in me to share some of your unpleasant lived experiences, and how you want to be supported in your recovery journey. My special thanks to the Swaziland National Psychiatric hospital management, the nurses and staff at the outpatients' departments, for their warm welcome of this study and accommodated me in their busy schedule. In addition, I am so grateful to Matron P. Dlamini, and Sister N. Mahlindza, who took this project to heart, and facilitated a smooth data collection process.

My mum and dad (Mrs. Agnes and Dr Anderson Nxumalo) who have not only imparted my life with principles of hard work and buoyancy, but have demonstrated this through their lives, and unlimited support. Even though you live in Swaziland, you never stopped communicating with me and giving me advice and information about the Swazi cultural perspective on living with mental illness. My deepest gratitude to my five amazing sisters (Phindile, Zanele, Zethu, Ntombikayise and Magugu), who continually encouraged me not to give up, and prayed for the success of this project.

My final innermost appreciation goes to my lovely family; my husband Dumisani who has ensured that my computer was functional at all times; my three precious children; Samiswa, MvuzoweNkosi and BusaNkosi, for editing my document, input with their advanced computer skills, and giving me time to pursue this project. All I can say is that I am looking forward to spending more time with you, and payback for all your sacrifices.

## **Dedication**

To my Heavenly Father, His Son Jesus Christ, and to the Holy Spirit; who started this work and have never ceased to infuse His inner strength in me, to see this project to completion.

# Table of Contents

List of tables .....	viii
List of figures.....	viii
Abbreviations.....	ix
Abstract.....	xi
Chapter 1.....	1
Background and Context of the Study.....	1
1.1 Overview.....	1
1.2 Justification of the study .....	2
1.3 Swaziland.....	5
1.3.1 General Health and Mental Health Services in Swaziland.....	6
1.3.2 Institutionalisation versus de-institutionalisation .....	8
1.4 Schizophrenia .....	9
1.4.1 Schizophrenia: Cost implications .....	14
1.4.2 Productivity, early Diagnosis and its link to Recovery .....	16
1.5 Public perceptions of mental illness in Swaziland .....	18
1.5.1 Mental Illness: An African perspective .....	19
1.6 The Phenomenon of Recovery.....	21
1.6.1 The history and models of recovery from mental illness .....	24
1.6.2 Models of recovery from mental illness .....	26
1.6.3 The place of language in the recovery process .....	36
1.7 Motivation of this study.....	40
1.8 Aim of the study .....	42
1.9 Study Objectives .....	42
1.10 Structure of the thesis .....	42
1.11 Conclusion .....	46
Chapter 2.....	47
Literature review.....	47

2.1 Introduction.....	47
2.2 Search Strategy for Research Articles .....	48
2.2.1 Inclusion and exclusion criteria .....	49
2.3.1 Purpose/Aim .....	52
2.3.2 Schizophrenia and recovery.....	53
2.3.3 Mental Illness and Recovery .....	55
2.3.4 Schizophrenia, Recovery and Women.....	56
2.3.5 Locations of Studies .....	56
2.3.6 Methodology.....	57
2.3.7 Participants and recruitment .....	58
2.3.8 Data Collection and Analysis .....	60
2.3.9 Findings: peoples' experiences of recovery .....	62
2.3.10 Definition of recovery.....	70
2.3.11 Hindrances of recovery.....	73
2.3.12 Enhancers of recovery .....	76
2.3.1.3 Rigour .....	79
2.4 Personal accounts of recovery from mental illness .....	80
2.5 Research Questions.....	90
2.6 Conclusion .....	90
Chapter 3.....	92
Methodology and Method.....	92
3.1 Introduction.....	92
<b>3.1.1 Research aim, questions and objects.....</b>	<b>92</b>
<b>3.2 Objectivism versus subjectivism .....</b>	<b>93</b>
<b>3.3 Qualitative research designs .....</b>	<b>96</b>
<b>3.4 Phenomenology .....</b>	<b>98</b>
<b>3.4.1 Husserl's Descriptive Transcendental phenomenology .....</b>	<b>98</b>
<b>3.4.2 Heidegger's hermeneutics phenomenology .....</b>	<b>100</b>
<b>3.4.3 Gadamer's Art of Hermeneutic.....</b>	<b>103</b>
<b>3.4.4 Ricoeur's Hermeneutic of the text.....</b>	<b>106</b>
<b>3.5 Phenomenology and Interpretive Phenomenological Analysis (IPA) .....</b>	<b>111</b>
<b>3.5.1 The Distinctiveness of IPA .....</b>	<b>113</b>

<b>3.5.1 Ethical Considerations .....</b>	<b>117</b>
<b>3.5.2 Participants .....</b>	<b>120</b>
<b>3.5.3 Data Collection .....</b>	<b>122</b>
<b>3.5.4 The Analysis .....</b>	<b>125</b>
<b>3.6 Rigour .....</b>	<b>130</b>
<b>3.7 Conclusion .....</b>	<b>133</b>
Chapter 4.....	136
Translation and Transliteration.....	136
4.1 Introduction.....	136
4.2 Rationale for including this chapter.....	136
4.3 Translation and Transliteration.....	136
4.3.1 Is it the ‘b’ that flies or ‘b’ to sleep or ‘b’ news .....	142
4.4 Definition of terms.....	143
4.5 Dealing with challenges of translation .....	146
4.6 Translation and Rigour .....	149
4.7 Conclusion .....	150
Chapter 5.....	152
Findings .....	152
5.1 Introduction.....	152
5.2 Overview of analysis .....	152
5.3 Identified of themes .....	155
5.3.1 Sorting and Grouping of Data.....	155
5.4 Overview of Themes: Super Ordinate and Subordinate .....	157
5.4.1 Super-ordinate Theme 1: The emotionality of the illness of the brain .....	159
5.4.2 Super-ordinate Theme 2: Pain! Living with the illness and with others .....	170
5.4.3 Super-ordinate Theme 3: Luhlanya lolu, ungalunaki (she is mad, just ignore her).....	179
5.4.4 Super-ordinate Theme 4: Kubancono (Feel better) .....	194
5.5 Conclusion .....	221
Chapter 6.....	224

Discussion.....	224
6.1 Introduction.....	224
6.3 Swazi women’s perceptions of the illness .....	226
6.3.1 Schizophrenia: ‘their’ definition.....	226
6.3.2 Culture and defining the cause of the illness .....	230
6.4 Impediments to recovery from the illness of the brain .....	232
6.4.1 At the hospital.....	232
6.4.2 At home and in the community .....	237
6.5 Perceptions of Recovery “Kubancono: Being better” .....	242
6.5.1 Recovery defined .....	243
6.6 Enhancers of recovery from the illness of the brain .....	247
6.6.1 At home and in the community .....	247
6.6.2 Hospital.....	254
6.7 Conclusion .....	258
Chapter 7.....	260
Conclusions and Implications.....	260
7.1 Introduction.....	260
7.2 Purpose .....	260
7.3 Research method appraisal .....	261
7.3.1 Research design .....	261
7.3.2 Rigour .....	264
7.3.3 Sensitivity to context .....	266
7.4 Living with Sifo sengcondvo (The Illness of The Brain) .....	268
7.5 Kubancono (being better) .....	268
7.6 Hindrances to recovery .....	269
7.6.1 Community & Home .....	269
7.6.2 Hospital.....	270
7.7 Enhancers of Recovery .....	271
7.7.1 Community and home.....	271
7.7.2 Hospital.....	271
7.8 Implications and Recommendations.....	271
7.8.1 Practice .....	272

7.8.2 Policy/stakeholders .....	277
7.8.3 Research.....	278
7.8.4 Education .....	280
7.8.5 Further research .....	280
7.9 Conclusion .....	281
7.10 Finally .....	283
7.10.1 Participants' quotes.....	283
References.....	286



## **List of tables**

<b>Table 1 Cost Implications for treating schizophrenia 2004-2005 .....</b>	<b>15</b>
<b>Table 2 Definitions of recovery .....</b>	<b>22</b>
<b>Table 3 Research studies and their methods .....</b>	<b>52</b>
<b>Table 4 Participants' information .....</b>	<b>154</b>
<b>Table 5 Super-ordinate and subordinate themes .....</b>	<b>157</b>
<b>Table 6 Research questions and themes .....</b>	<b>226</b>
<b>Table 7 Recovery: Swazi women's perspective .....</b>	<b>246</b>

## **List of figures**

<b>Figure 1 Map of Southern Africa with Swaziland .....</b>	<b>5</b>
<b>Figure 2 A recovery focused service by SCN, adopted from Le Boutillier et al., 2011.....</b>	<b>32</b>
<b>Figure 3 The Research Structure .....</b>	<b>45</b>

## **Abbreviations**

AIDS	Acquired Immune deficiency syndrome
BAME	Black Asian and Minority Ethnic group
CRPD	United Nations Convention on the Rights of Person with Disabilities
HIV	Human Immuno Deficiency virus
IPA	Interpretive Phenomenological Analysis
IPSS	International Pilot Study of Schizophrenia
PORT	Patient Outcomes Research Team
MHA	Mental Health Act
MOH	Ministry of Health
OPD	Out Patients' Department
PHC	Primary Health Care
NICE	National Institute of Clinical Excellence
IMHRO	International Mental Health Research Organisation
SNPH	Swaziland National Psychiatric Hospital
SU	Service User
WHO	World Health Organisation
LES	Lived Expertise of Schizophrenia

**“The message is clear and unequivocal:  
mental health – neglected for far too long – is  
crucial to the overall well-being of  
individuals, societies and countries, and must  
be universally regarded in a new light”**

(WHO, Nations for Mental Health Final Report, 2001, p. 63)

## **Abstract**

**Background:** Recovery from severe mental illness, namely schizophrenia, is a contemporary issue. Globally, twenty-four million people live with schizophrenia, men and women being equally affected. Of those diagnosed with schizophrenia, 90% are said to be living in developing countries. However, while Western culture has recognised the centrality of service user expertise within the process of recovery, little attention has been given to those living with such illness in developing countries, such as those in Sub-Saharan Africa, Swaziland being one of them. Schizophrenia is of great concern in Swaziland, as it is most prevalent amongst the 25 to 45 year olds, compromising productivity and adversely affecting the country's economy. While both men and women contribute to the Swazi economy, and can be equally affected by the illness, there appears to be stigma and discrimination of women in the provision of mental health care. This study explored the perceptions, experiences and meaning of recovery for Swazi women living with schizophrenia with a view to improving the mental health care offered to them in Swaziland.

**Method:** Qualitative phenomenology was used to guide the research process. A convenient purposive sample of fifteen Swazi women, diagnosed with schizophrenia, was recruited from the Swaziland National Psychiatric Hospital (SNPH) out patients' department. One to one, face to face interviews were conducted, audio recorded, translated and transcribed by the researcher. Interpretive phenomenological analysis (IPA) was used to analyse the data.

**Findings:** More than half of the women defined recovery in terms of remission of symptoms, and acknowledged the importance of taking prescribed medication in promoting their recovery. The majority of participants identified helping others, involvement in community activities and spirituality as important enhancers of their recovery. Health professionals working at SNPH both promoted and hindered their recovery.

**Conclusion:** The findings of this study add to a developing body of knowledge regarding women's recovery from schizophrenia in Sub-Saharan Africa, having implications for future African/Swazi consumer focused mental health services.

# **Chapter 1**

## **Background and Context of the Study**

### **1.1 Overview**

My passion for focusing this study on women was born out of the fact that I am the first-born woman in my family, followed by five lovely sisters, I therefore believe and am passionate about women and their potential. I have observed that most Swazi women experience a lot of hardship and difficulties, especially because of the patriarchal dominated society. There seems to be the added strain of stigma, towards those women living with schizophrenia. During my clinical practice as a general and mental health nurse working in Swaziland, I have observed how some professionals stigmatise people living with mental illness, in general, not just those diagnosed with schizophrenia. For example, I worked in a female medical ward for five years where we admitted people referred from the Swaziland National Psychiatric Hospital (SNPH), and have heard nurses labelling people as “lesikizo” transliterated “this schizophrenic.” A woman diagnosed with schizophrenia was admitted to my ward, with ‘confusion of unknown origin’, and passed urine in her bed, on several occasions. Staffs noted that she got out of bed, wandered around the ward and needed support during ambulation. The ward manager quickly decided that she needed cot sides to prevent her from getting out of bed. I then noticed that she regained her ability to hold a normal conversation and all she said was “I only wanted to go to the toilet.”

This study was born out of my quest to give a voice to women living with schizophrenia, in a society that seems to disadvantage their recovery. This first chapter gives a general description of the country in which the study takes place, background information about schizophrenia and the process of recovery. A critical review of previous studies focusing on schizophrenia and recovery

follows in chapter 2. The theoretical framework which guided this research and the method used to conduct my study is detailed in chapter 3. Chapter 4 describe issues of translation and transliteration, because of the bilingual approach of this study. Findings are delineated in chapter 5, and they are discussed in chapter 6. The final chapter (7) is that of the study's implications and recommendations.

The main focus of this chapter is to provide the background and context of the study. The chapter starts with my justification for undertaking the study, followed by a description of the geographical location of Swaziland, and an overview of the mental health system. This is then followed by a brief definition of schizophrenia and some of the meanings ascribed to this diagnosis in Swazi society. The reality of the phenomenon under investigation, recovery, is then defined and discussed further on in the chapter. The final part of this chapter will offer a clear articulation of the research questions, aims and the objectives of the study.

## **1.2 Justification of the study**

The aim of this qualitative phenomenological study was to gain an understanding of Swazi women's experiences of living with schizophrenia, and their perceptions and experiences of recovery from it. The setting for the study was the Swaziland National Psychiatric Hospital (SNPH), in Manzini, Swaziland. From my experience and observation as a Swazi woman and a qualified mental health nurse, individuals living with mental illness in Swaziland, especially those diagnosed with schizophrenia, are not adequately involved in their care. As a result, support given is not necessarily patient led. Likewise, there is little information about women and recovery from mental illness, including schizophrenia, and, perhaps the fact that schizophrenia affects more men than women has lead researchers to focus more on man than women (McKay, 2010).

Consequently, the broadening of knowledge about the experiences and needs of Swazi women living with schizophrenia could lead to mental health services being more sensitive to their needs.

Many Swazi women are the bread winners within their house-holds, either because they were abandoned (with the children) by their partners, or they have had to assume this position because their partner relinquished their role; and /or because men are pre-occupied with other things. Sadly, Swazi women living with mental illness commonly report physical, emotional and sexual abuse by men, which hinders their recovery (Reza et al., 2009). As a result, women's changed status, their roles and expectations in the Swazi society possibly make their experience of living with schizophrenia different to those of men (Chernomas et al., 2000; Manuel et al., 2012). This is one of the reasons triggering my curiosity to find out about their unique experiences of the living with schizophrenia, and how they believe they could best be supported in easing the burden of living with the illness, along with the pressures brought about by their roles and responsibilities. Additionally, my interest in undertaking this study emanated from my desire, not only to know women's perspectives of recovery, but to also use the findings to influence the development of service user led mental health services and policy formulation in Swaziland.

In addition to my observations from practice, I have also had experience of mental illness within my family, with first-hand experience of the devastating changes and challenges it brings. After two of my close relatives had acute episodes of severe mental illness, I had opportunities to talk with both about their experiences of the illness, and how each became 'better' or recovered from their illness. One of them, the eldest relative, explained: *"I felt valued and important when you*

*visited me in hospital and talked to me about my thoughts, and desires. I wanted to talk to someone and tell them how I felt and what I needed.*” My second relative stayed in hospital for two months during her first admission. On my arrival from the UK I visited her at the hospital and she told me that she wanted to be discharged home. This was not received well by health professionals at the SNPH, they argued that she needed to remain in hospital, by stating that she was not well enough to be cared for at home. My younger relative described her stay in the hospital as *“All I did was to take medication, and wander around the hospital for the whole day, while experiencing so much distress from the noise made by the other patients who screamed and shouted, day and night.”* In less than two weeks, with family support, she soon established her routine and was able to return to university to complete her degree. Although she has had difficult times and distressing moments, she continues to receive support from the community and her family, where she is able to share her thoughts and feelings, while working out coping strategies to deal with presenting issues. Consequently, through the support they received neither relative has had any further hospital admissions. My younger relative is now working, participating in a number of community activities, has completed a second degree, and is getting ready for her wedding.

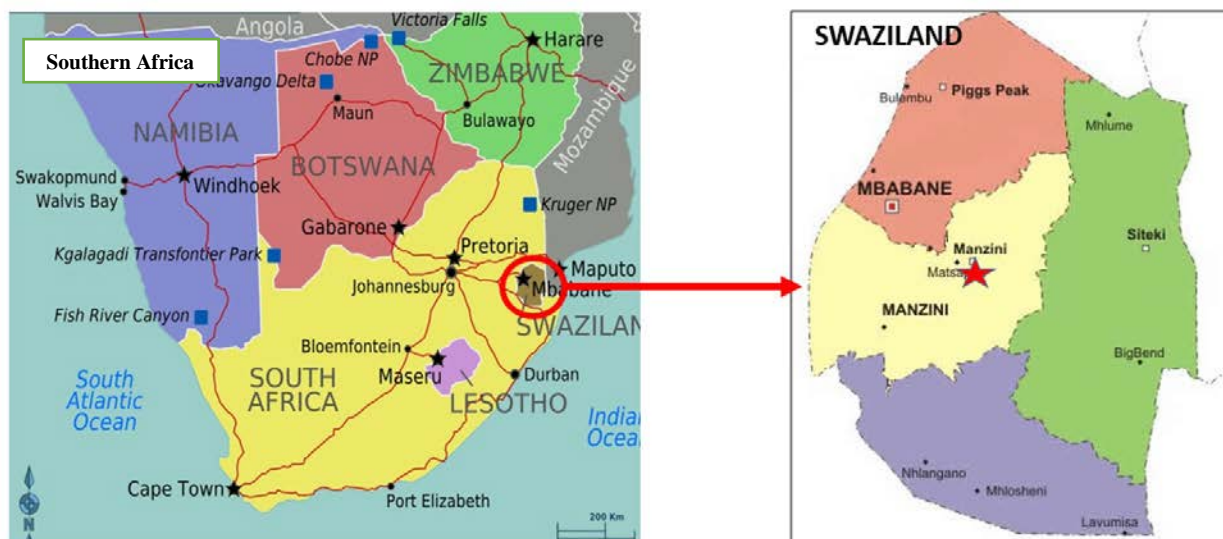
My aim in undertaking this study was to provide user-led knowledge and insight into how the needs of women recovering from schizophrenia might be best addressed by the Swazi mental health care system. While people living with mental illness each have a unique journey to recovery, the lived experiences of my relatives’ recovery prompted me to think about what could be done to make a difference to the lives of individuals, and in particular women living with schizophrenia in Swaziland. Hearing my relatives’ stories made me think about the significance of individuals, living with mental illness, having opportunity to talk about their experiences and how hearing their



voice could lead to a better understanding of the processes of recovery, which in turn could influence the way mental health services are provided (Holloway & Wheeler, 1996; Weston, 2011).

### 1.3 Swaziland

Swaziland is situated in the southern part of Africa, in the area commonly known as the Sub-Saharan region. It is a 17,363 km<sup>2</sup> landlocked country, with 95% of its border being South Africa, and 5% Mozambique. It has a population of 1.2 million people. There are four geographical regions; Highveld, Middleveld, Lowveld and the Lubombo (Foreign Commonwealth Office, 2011). Mbabane is the capital and largest city, and Manzini is the second largest city situated at the hub or centre of the country. The SNPH is located at Manzini. Figure 1 below shows the location of Swaziland in Southern Africa and its neighbouring countries.



**Figure 1 Map of Southern Africa with Swaziland**

### **1.3.1 General Health and Mental Health Services in Swaziland**

Swaziland has some specific health challenges. It has the highest HIV/AIDS infection rate in the world, with a prevalence rate of 25 % among the 15-45year olds (UNAIDS Gap report, 2014). Burns (2011) acknowledged that there is clear evidence that HIV/AIDS increases the incidents of mental illness. Therefore, it is likely that those living with HIV/AIDS will also experience mental illness. Mental illness in Swaziland is most prevalent amongst 25 to 45 years old. Due to the economic strain, both of these health problems are of great concern to Swaziland, as these age groups are the most productive in terms of the workforce and, consequentially, the country's economy.

With regards to health, low-income countries (such as Swaziland) allocate only a very small, if any, percentage of the overall health budget to mental health services. As such, mental health care tends to be institutionalized, because decentralization of services to the community requires more financial resources (Saxena et. al., 2007). Likewise, it is suggested that only 2% of health budgets in sub-Saharan Africa are allocated to mental health, leading to underfunding in many of these countries (Bader, 2011). According to the World Health Organisation (WHO), the government of Swaziland does not invest adequate expenditures within mental health services, including those of the SNPH, the country's only mental health hospital (WHO, 2011).

The SNPH is a 150-bed psychiatric hospital, located at Manzini (WHO, 2011). From my general observation while working at the hospital, and a comment by one of the nursing sisters, there are approximately 400 in-patients in the five units that comprise the hospital, at any given time. In addition to the hospital there are three out- patients' clinics located in each of the other three

regions of the country. The main purpose of these units is to provide community mental health services on an out-patient basis. Of those admitted to SNPH, 33.9% have a diagnosis of schizophrenia, with 26.4% being between the ages of 20-39 years, (Swaziland Ministry of Health, 2010). Regardless of the magnitude of the mental health challenges, Swaziland does not have an official mental health policy (WHO, 2011).

The Swaziland government is the primary source of funding to the country's health sectors. However, businesses and religious organisations contribute to some of the community based health facilities (Myeni & McGrath 1990; Economic Planning Office 1992; Upvall 1992; WHO, 2011). The general public pay a subsidised fee for health interventions of any kind, except treatment and management for mental illness' related conditions, which is freely provided to the nation. In 1983 the ministry of health in Swaziland introduced the Primary Health Care (PHC) strategy, in its endeavour to deal with the country's major problems: maternal and child health; infectious and communicable diseases; and nutritional deficiency (MOH 1983). While the problems listed did not include mental illnesses, during subsequent years Swaziland experienced an increase in the number of admissions to the SNPH, an indication that the prevailing physical problems had adverse effects on people's mental well-being (MOH 1983).

The PHC strategy has components which serve as a guide for its implementation. One such component is that of inter-sectoral collaboration. However, on evaluation of the effectiveness of the PHC strategy, inter-sectoral collaboration was found lacking in some important areas (Sukati, 1997). While collaboration amongst health professionals is imperative to the success of the

strategy, the health sector has not been able to incorporate core recipients (SUs) of mental health services within this process (Sukati, 1997). As a result, there has not been a clear understanding of service users' needs and/or perceptions of what they are looking for in terms of care and support. The present study is in keeping with that of Sukati's (1997) evaluation, in as much as one of her recommendations highlighted the need to get in touch with members of the community to discover their perceptions of what hinders and enhance health, with a view to using such data to evaluate health care and adapt goals and policies accordingly. Additionally, this could perhaps facilitate the move from hospital focused mental health care to one which is more community based, with promotion and prevention being foregrounded.

### **1.3.2 Institutionalisation versus de-institutionalisation**

In 1954 the highest number of hospitalised patients diagnosed with schizophrenia in England and Wales was recorded (McLynn, 1996). The de-institutionalisation of people living with mental illness in the 1960s was made possible by the introduction of phenothiazines, such as Chlorpromazine (Largactil), and the repeal of the Lunacy Act, the latter being replaced with the Mental Health Act of 1959. Due to these advances in medicine and changes in legislation the trend shifted, and improved mental health services equated to the majority of people being treated in the community (Lieberman & Kopelowicz, 2002). Such a move has since been associated with enhanced recovery from mental illness (Shean, 2010). While this trend is evidenced in developed countries, such as the United Kingdom (UK), it is not the same in developing countries such as Swaziland and South Africa (Botha et al., 2006). For example, in Swaziland the national 150 bed psychiatric hospital is overcrowded, with people being admitted at approximately more than double the number of available hospital beds. This being the case, it appears that Swaziland has a

long way to go in providing appropriate care and support to enhance people's recovery process. For example, there is no evidence to support a rigorous initiative of deinstitutionalising mental health practise; a strategy that has been advocated as significant in enhancing recovery from mental illness, and one which is cost effective (Ralph et al., 2002; Allot et al., 2003; May, 2003). The SNPH is the only hospital in the country and it seems as if attempts to create community based psychiatric clinics has been challenged, as a number of these clinics have been changed to accomodate other health care service usage. For example, one of the community centres is now being used to roll out antiretroviral therapy.

Early diagnosis, along with the use of recovery focused strategies as an integral part of treatment, have been identified by users of mental health services to be paramount in their recovery, as well as reducing the financial implications of managing and treating the illness (The Schizophrenia Commission, 2012). These two important issues possibly indicate the need for using a recovery based model for mental health care in Swaziland, with the aim of reducing the number of days people stay in hospital, and promote quality of life for individuals living with mental illness. However, this will be difficult to achieve without gaining an understanding of what people in Swaziland diagnosed with schizophrenia perceive recovery to be.

#### **1.4 Schizophrenia**

The word 'schizophrenia' originates from the Greek word 'skhizo' (split) and 'phrenia' (mind) (Townsend, 2005). One stereotype belief that promotes stigmatisation of individuals diagnosed with schizophrenia is that they have two personalities, sometimes referred to as a 'split personality,' and are therefore violent and unpredictable, because they switch from one personality to the other (Botha et al., 2006; Gillam, 2006). However, rather than being a danger to others,

people living with schizophrenia have a high risk of suicide. Likewise, it has also been suggested that members of the general public pose a greater risk of violence than those living with schizophrenia (Frisch & Frisch, 2006). Frisch and Frisch (2006) defined schizophrenia as a *“mental disorder characterised by disordered thoughts, hallucinations and delusions,”* (p. 228).

Emil Kraepelin was the first to describe schizophrenia in the nineteenth century (Anderson, 1995; McLynn, 1996), and Bleuler was the first to classify signs and symptoms of schizophrenia in 1950. These became known as Bleuler’s A’s: Autistic thoughts, Affective incongruence, Association loosening and Ambivalence (Paolo Fusar-Poli & Politi, 2008). At the end of the 1950s early 1960s, Schneider, in trying to make formulating a diagnosis easy, categorised the signs and symptoms of schizophrenia, identifying what are now referred to as ‘first rank symptoms’, these included; delusional perception, auditory hallucinations, disturbance of thinking and passivity phenomenon (Paolo Fusar-Poli & Politi, 2008).

Since its first description, schizophrenia bears negative implications, resulting in stigmatisation of those living with this illness. Different authors (Andreasen, 1999; McLynn, 1996; Toner, 2000; Rice, 2006; Knapp et al., 2009; Snowden, 2009) use pessimistic phrases to define schizophrenia. For example: chronic illness with long-lasting negative societal impact (Andreasen, 1999); the most serious mental health condition (Toner, 2000; Rice, 2006); a debilitating condition that affects the thought process (Snowden, 2009); a major psychotic disorder (McLynn, 1996; Toner, 2000; Rice, 2006); a mental condition that can last a life time (Andreasen, 1999; McLynn, 1996); one of the most serious of all mental conditions (Toner, 2000); complex and severe mental illness

(Rice, 2006); persistent, chronic and serious condition (Snowden, 2009); a devastating illness (McLynn, 1996); a frightening, disruptive and disabling psychiatric illness (Knapp et al., 2009); a broad brain sweeping disease (Andreasen, 1999; McLynn, 1996); a disease that causes a continuous downhill course (Harrow & Jobe, 2005). The above descriptions of schizophrenia possibly reinforce the negativity associated with this mental illness, thus, the belief that people living with schizophrenia never recover. Nevertheless, other studies (Harding, et al, 1987; Torgalsboen & Rund, 2002; Harrow & Jobe, 2005; Bradshaw, et al., 2007; Hopper et al, 2007; Torgalsboen & Rund, 2010) suggest that schizophrenia, while still cited as one of the major long term illnesses, have also encompassed the notion of recovery as an important process that should be considered as integral to the illness. This has been suggested as people diagnosed with schizophrenia have verbalised and evidenced that recovery does occur (Harding, et al, 1987; Torgalsboen & Rund, 2002; Bradshaw et al., 2007; Thara et al, 2007; Torgalsboen & Rund, 2010; Economou et al, 2011).

Whilst Schizophrenia is described as an enduring and severe form of mental illness, characterized by distorted perceptions, thinking and emotions, recent studies have shown that recovery can be enhanced through therapeutic engagement (Keopelowicz, et al., 2007). Therapeutic engagement, can facilitate change in the person's thought process, behaviour, attitudes, self-efficacy, emotional distress and perceptions (Keopelowicz, et al., 2007) and it is believed to be central to the recovery process, empowering people diagnosed with mental illness by providing them with the information and skills to manage their illness (Hewitt & Coffey, 2005; McGuire-Snieckus et al., 2007). The notion of empowerment and people gaining the skills to manage their illness has in more recent years gathered momentum. In the past recovery was associated with being 'cured' from mental

illness or getting back to 'normal', an ideology based on a medical perspective of recovery (Collier, 2010). The medical model has tended to focus on the signs and symptoms of schizophrenia as an important indicator of recovery, people living with schizophrenia, such as Leete (1989) and Deegan (1995) describe recovery as not just the absence of symptoms, but the ability to learn and grow from the experience of mental illness. The latter is especially pertinent when having to adapt to limitations resulting from the illness, while developing coping strategies to deal with day to day challenges (Repper & Perkins, 2003).

More recently, recovery has been defined as an individual process, whereby a person is able to take control of their life, to make it personally meaningful and satisfying (Young & Ensing, 1999; Smith, 2000; Ridgway, 2001; Tooth et al., 2003; Jenkins et al., 2005; Mancini et al., 2005; Bradshaw et al., 2006; Noiseux & Ricard, 2008; Pitt et al., 2007; Piat et al., 2009; McKay, 2010; Romano et al., 2010; Leam et al., 2011; Kalathil et al., 2011; Patterson et al., 2011; Beck et al., 2012; Wood et al., 2013). This contemporary perception of recovery has the potential to empower, encourage and enhance realistic hope for those living with mental illness.

Globally, there has been an increase in the number of people living with schizophrenia from 20 million to over 25 million people, and therefore considered a major health problem (Hopper et al, 2007; Myers, 2010). Of these, 90% are said to be living in developing countries (Rossler et al, 2005; McGrath et al, 2008). Schizophrenia affects more than five people per 1,000 between 25 – 45 years of age, and it is suggested that one person in every 100 will experience a schizophrenic episode during their life time (Rossler et al., 2005).



Schizophrenia is said to be the most common type of serious and enduring mental illness, and its prevalence rate varies between countries (Bhugra, 2005). For example, in China, one of the fastest growing industrial countries, schizophrenia has the highest prevalence of about 2.82 per 100 000 population (Thara et al., 2007). Likewise, although the prevalence rate of schizophrenia is the same in rural and urban communities, it is thought to be higher amongst vulnerable groups such as immigrants and homeless people (Bhugra, 2005; Saha et al., 2005; Hopper et al, 2007).

Sajatovic et al., (2005) assert that the experiences of recovery from schizophrenia are more likely to be different between males and females, as these may be influenced by cultural gender identity. Sajatovic et al. (2005) define gender identity as “*the subjective experience of one’s individuality as male or female.*” (p.98). In their paper on gender identity and implications for recovery, they suggest research evidence indicates women diagnosed with schizophrenia recover much quicker than their male counterparts, with fewer cases of women relapsing after being discharged from hospital to the community (Sajatovic et al., 2005). Chernomas et al. (2000), when studying the perspectives of women living with schizophrenia, found that regardless of them feeling that a lack of focus on their illness had made them invisible as women, they had a continuous desire and hope that their situation would change for the better. Similarly, it has been suggested that mental health services in the UK are not always sensitive to the needs of women (Warne & McAndrew, 2007), and the researcher has observed a similar trend in Swaziland. As such, knowledge of how Swazi women experience recovery from schizophrenia is significant in ensuring services and resources are supportive of their recovery process. Due to their diverse experiences of living in a patriarchal society, dominated by socio-cultural influences, perhaps the needs of Swazi women living with schizophrenia are better investigated exclusively; with a view of promoting quality care, and

possibly conducting further research which will either focus on men's experience and/or compare the needs of both genders.

#### **1.4.1 Schizophrenia: Cost implications**

There is a positive correlation between the use of recovery focused interventions and cost effectiveness regarding the treatment and management of people diagnosed with schizophrenia. According to the International Mental Health Research Organisation (IMHRO, 2010) research on schizophrenia receives the smallest amount of funds compared to other diseases worldwide. In November, 2011 'Rethink Mental Illness', a charity that supports individuals and families affected by mental illness in England, established 'The Schizophrenia Commission.' The purpose of this group was to evaluate mental health services in England and to identify strategies of how improvements could be made, while curbing the treatment and management costs. The commission, chaired by Professor Sir Robin Murray, a psychiatrist, consisted of fourteen experts in the field of mental health. Data was collected over a twelve month period, through formal sessions and using online surveys. Responses came from people living with schizophrenia, their family members, carers and friends; as well as health and social care professionals (The Schizophrenia Commission, 2012). One of the findings from the commission focused on productivity. During the acute/onset stage of the illness, those diagnosed with schizophrenia became less productive because they were unable to work, with this having a negative impact on the wider economy. In order to counteract this problem it is imperative for health services to focus on early diagnoses and treatment of schizophrenia, and the reinstatement of those diagnosed to optimise productivity through quicker reintegration into the community. The Schizophrenia Commission (2012) pointed out that the £11.8 billion a year spent in the management and treatment of people with schizophrenia could be reduced by focusing on prevention and early diagnosis and

treatment. It was considered that this, as a strategy, could promote quality of life for people living with schizophrenia, while at the same time saving millions of pounds (The schizophrenia commission, 2012).

Prior to the setting up of the Schizophrenia Commission, Mangalore and Knapp (2007) conducted a study on the cost of schizophrenia in England. Their data was collected from the Schizophrenia Care and Assessment (UK-SCAP) survey, Psychiatric Morbidity Survey, the Department of Health, and other government publications. Table 1 below summarizes some of the costs implications of treating people diagnosed with schizophrenia during the year 2004 - 2005.

***Table 1 Cost Implications for treating schizophrenia 2004-2005***

<b>AREAS OF IMPACT</b>	<b>TOTAL COST IN GBP</b>
Direct treatment	2 Billion
Loss of productivity due to: unemployment, absence from work, and premature death	3.4 Billion
Cost of Care to Families	615 Million
Loss of carers productivity	32 Million
Cost to the Criminal Justice	1 Million
Paid out in Benefits	570 Million
Administration of Benefit payment	14 Million

**(Mangalore & Knapp, 2007)**

In a systematic review of literature to investigate the global cost of schizophrenia, Knapp et al. (2004) identified the total national cost of managing patients with schizophrenia in the United Kingdom to be ‘£2.1 billion’ (p. 281). Between 2004 and 2007 this expenditure tripled, with the national cost being recorded at ‘£6.7 billion’ (Mangalore & Knapp 2007). The situation is similar

in the United States of America (USA) where \$62 billion per year is used in taking care of mentally ill individuals during the acute stage of schizophrenia; approximately \$125,000 per person, per year. Additionally, \$1.25 million is lost by male persons diagnosed with schizophrenia in late adolescence because of non-productivity and unemployment (Kopelowicz, et al., 2007). In Knapp et al.'s (2004) systematic review of the global cost of schizophrenia, the authors only highlighted cost implications of one African country, Nigeria. For the purpose of comparing different global regions, it would be interesting to know the cost implications for other regions, such as Asia and South America.

The cost of caring for people with schizophrenia indicates that there is a need to do robust research if cost effective strategies are to be established. Even though developed countries have evidenced the financial benefits of using a recovery model in the care of individuals living with schizophrenia, there is no evidence to support the same in developing countries. The cost benefits, in financial and quality of life terms, of recovery focused health services was highlighted by a member of The schizophrenia commission (2012), Alison Brabban, a consultant clinical psychologist and clinical lead in early intervention psychosis;

*“I work in Early Intervention in Psychosis and see the difference these services make to people’s lives. It’s not just intervening early that makes the difference. It’s about staff who believe in recovery, delivering individualised, high quality care. Early Intervention Psychosis (EIP) services improve outcomes, save money and are valued by patients and carers alike. This must be the success story of mental health services” (p.17).*

#### **1.4.2 Productivity, early Diagnosis and its link to Recovery**

Early diagnosis of schizophrenia and recovery focus interventions, result in reduced hospital days, good prognosis, and better quality of life (Harrow & Jobe, 2005). For some, (Munetz & Frese, 2001; Chovil, 2005) hospitals can hinder patients’ recovery from mental illness, as those using

service are thought to learn feelings of hopelessness. In other words, keeping patients in hospital for long periods of time promotes dependency and learned helplessness. As a result, those patients who spend longer periods in hospital will not recover as quickly as those who spend less time in hospitals. For this reason, early diagnosis, treatment and early discharge are considered important aspects in promoting recovery from mental illness (Harrow & Jobe, 2005).

Some of the issues of early diagnosis of schizophrenia have been identified as: variations in the diagnostic guidelines, fear of stigmatisation and the accessibility of mental health services (Peebles et al., 2007; Bhugra, 2010; The Schizophrenia Commission, 2012). Early diagnosis is reliant on the person meeting criteria specified in the DSM-5 (2013) and/or the ICD-10 (2010), diagnostic tools used by the medical profession. For example, along with including symptoms of schizophrenia both manuals stipulate that at least one of the symptoms must be present for at least one month before a diagnosis of schizophrenia is made. However, the DSM-5 (2013) also stipulates that the symptoms must be persistent for at least six months, and as such, clinicians may become reluctant to give SUs an early diagnosis, thereby prolonging commencement of the recovery process (Bhurgra, 2010).

According to the findings of The Schizophrenia Commission in England (2012), only 8% of individuals living with schizophrenia are employed, even though they have recovered and have a desire to work. One reason cited for this situation is that people living with schizophrenia experience public stigmatization; where they are denied access to public privileges because of their diagnosis. Likewise, people living with schizophrenia often experience self-stigma, believing that

they will be discriminate against by the general public, because of their diagnosis, consequently refusing to engage with mental health services, or denying the diagnosis of schizophrenia (Kondrat & Teater, 2009). This has negative implications for their recovery and the prognosis of the illness (Peebles, et al, 2007; Bhurga, 2010). Kondrat and Teater (2009) state that recovery is a powerful mode of empowering SUs in dealing with stigma, by supporting them to change the way they think about themselves and how they are perceived by the public. An optimistic view of one's self will hopefully drive SUs to reach out to those mental health services provided for those living with schizophrenia, leading to enhanced recovery.

Gaining access to mental health services in England is one of the challenges that hinders the process of recovery from schizophrenia, as accessibility to supportive services is often limited, especially to minority groups (The Schizophrenia Commission, 2012). For example, the Schizophrenia Commission acknowledged that even though NICE (2009) emphasised the accessibility of CBT to individuals living with schizophrenia, only one in ten have access to these services. The report also indicates that such therapeutic approaches do not address the cultural beliefs of Black Minority Ethnic groups (BME), thereby discouraging such groups from using the services.

### **1.5 Public perceptions of mental illness in Swaziland**

To date and as far as I am aware, Swazis associate being mentally healthy as one's ability to think or reason coherently, and being able to cope with the challenges of daily living. Mentally well individuals are seen as those who are able to live in harmony with other members of society. Such

people might not always be liked or always be in agreement with each other, but they live harmoniously with each other's differences.

In contrast to the above, a mentally unwell person presents the opposite attributes of living in harmony with other members of the society. These include unacceptable and unpredictable behaviour, and actions that pose danger to others in the community. Such beliefs encourage Swazis to be afraid of mentally ill people. The general name for mental illness is 'kuhlanya' or madness. Unlike the situation in developed countries whereby mental illness is classified, Swazis generally call any abnormal behaviour or reasoning as madness. There is no Swazi word for Schizophrenia, a person presenting with symptoms similar to those evidenced in the DSM or ICD is said to be mad or mentally unwell.

### **1.5.1 Mental Illness: An African perspective**

South Africa, like most developing countries, experiences a number of challenges in supporting those living with mental illness. For example, a limited financial allocation to mental health care has led to scarcity of mental health services, especially in rural areas (Alonso-Betancour & Morales-Herrera, 2010; Burns, 2011). In her endeavours to improve the quality of mental health services, the South Africa government introduced the Mental Health Act (MHA, 2002), and also became a signatory of the United Nations Convention on the Rights of Person with Disabilities (CRPD) in 2007. According to Burns (2011), the significance of these initiatives was to ensure that human rights are adhered to, and that those who violate such rights are dealt with accordingly. Some of the major principles of the South African MHA are; the de-centralisation of mental health services from hospitals to community, the incorporation of mental health into primary health care,

rehabilitation of individuals diagnosed with mental illness, and the promotion of an individual's autonomy.

Unfortunately, all the plans and efforts to address the gap in mental health care in South Africa were compromised due to lack of funding to implement the initiatives (Burns, 2011). Professionals did not receive the appropriate training to implement the planned changes, and there was a lack of mental health rehabilitation programmes (Burns, 2011). However, Alonso-Betancour & Morales-Herrera (2010) acknowledged the existence of rehabilitation programmes in South African communities, but noted that they were not designed by patients. As such, the ability of the rehabilitation programmes to address the needs of those who receive them became a major concern.

In addition to a lack of well-designed rehabilitation programmes, stigma amongst people living with mental illness in South Africa was also found to hinder recovery. Studies undertaken by Hugo et al. (2003) and Botha et al. (2006) indicated that people living with mental illness in South Africa experience internal and external stigmatisation and, as a consequence, they suffer in silence and do not seek help due to fear of how others will react to their illness. In most African societies people living with mental illness are not only estranged from society, but are also abused along with their families (Gureje et al., 2007; Crabb et al., 2012). One of the major strategies in dealing with stigmatization and promoting recovery is to educate the public about mental health and illness (Hugo et al., 2003; Botha et al., 2006). In addition, if recovery is to be promoted, there is a need to address cultural influences that impact on stigma in relation to those with mental health problems (Botha et al., 2006; Mosotho et al., 2008). For example, some African communities



believe that people living with mental illness possibly offended the gods and/or ancestors, and therefore deserve no support (Gureje et al., 2007). As such, those living within these communities are less likely to support those diagnosed with mental illness. Also, signs of mental illness may be defined and/or described differently in different communities. For example, from my general knowledge of Swaziland, some people believe that a person having a grand-mal seizure is ‘possessed with animals’; while hearing voices could be associated with a call to be become a traditional healer. As such the management for these two presentations will be different. In light of this, a clear understanding of the cultural difference in society is paramount if mental health and recovery are to be promoted (Mosotho et al., 2008).

## **1.6 The Phenomenon of Recovery**

According to the Oxford English dictionary the word recovery means “to get back: regain” or “to restore (oneself) to a normal state” (Allen, 1990). While this definition is clear and straight forward, the definition of recovery from mental illness is multifaceted and is dependent on the philosophical approach of those defining it. For example, in an attempt to describe recovery, the following polarised words ascribed to the phenomenon are identified in Table 2

***Table 2 Definitions of recovery***

Objective	VS	Subjective (Papadopoulos et al., 2013)
Cure	VS	Adaptation (Leete, 1989; Deegan, 1995)
Medical model	VS	Consumer led model (Deegan, 1995; Repper & Perkins, 2003; Jenkins & Carpenter-Song, 2005; Piat et al., 2009)
Traditional	VS	Contemporary (Papadopoulos et al., 2013)
Institutionalisation	VS	Actualising one's potential (Munetz & Frese, 2001)
Clinical	VS	Personal (Slade, 2009)

From the polarised words used to describe the phenomenon of recovery, the words used in the left hand column represent a paternalistic approach whereby the prevailing medical model dictates that the health professional is expert in judging when recovery has occurred. Words such as 'objective' and 'medical model' imply that a set of symptoms have been identified and are in keeping with positivism, whereby a single truth exists and it is through knowing this that judgements can be made. However, in contrast to this is the opposing words indicate an individualistic perspective of recovery; one which is meaningful to individual service users; who are experts in their own life trajectory.

The best way of defining recovery is from the perspective of those who have experience of recovering from mental illness (Deegan, 1995; Ralph, 2000; Ng et al., 2012). While SU focused definitions of recovery might bring diverse meaning, its value is in revealing common features of how this phenomenon is defined. Ralph (2000) states that the concept of recovery was never

heard of, nor accepted until the late 1980s and the beginning of the 1990s, when users of mental health services started coming out and sharing how they recovered from mental illness.

According to Anthony (1993) and Repper & Perkins (2003) those who have experienced mental illness define recovery as;

*“a deeply personal, unique process of changing one’s attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by illness. Recovery involves the development of new meaning and purpose in one’s life as one grows beyond the catastrophic effects of mental illness.”* (p.7; p.46)

In the past recovery was often defined from a medical perspective and was associated with being ‘cured from’, or the ‘remission of’, all symptoms of mental illness. This perspective was restrictive in the sense that those diagnosed with mental illness, such as schizophrenia, could only be considered to have recovered if they experienced no symptoms of the illness. However, those who have experience of living with schizophrenia associate recovery with and/or without symptoms (Torgalsboen & Rund, 2010; Albert et al., 2011; Patterson et al., 2011; Roe et al., 2011; Ng et al., 2012).

More recently, recovery from mental illness has been defined as an individual process whereby a person is able to take control of their life to make it personally meaningful and satisfying (Collier & Yates-Bolton, 2011; Patterson et al., 2011; Roe et al., 2011). This perception of recovery has the potential to empower, encourage and enhance realistic hope for those living with mental illness. However, these definitions of recovery are in the context of the developed world, and this being the case it is important to understand the experiences of recovery from schizophrenia as perceived by those living in undeveloped countries. Recovery is what people experience themselves as they become empowered to manage their own lives in a manner that

allows them to achieve a fulfilling meaningful life and gain a sense of belonging in their particular society and/or culture.

Along with the varied definitions of recovery, those with lived experiences of mental illness contend with the actual name that should be given to the description of their experience. The word healing has been disregarded because of its tendency to imply recuperation from either a trauma or injury, so that words like transformation and being an overcomer are considered as more relevant (Ralph et al., 2000). Transformation has been associated with the fact that the experience of living with the mental illness has changed patients' lives so that they have or continue to overcome challenges associated with the experience; and as such (even though experienced differently) they perceive themselves as having the ability to help and support others going through similar experience (Ralph et al., 2000).

#### **1.6.1 The history and models of recovery from mental illness**

During the past 30 years there has been an increased focus on recovery, with a number of studies supporting the fact that those diagnosed with schizophrenia or mental illness actually experience recovery (Harding et al., 1987b; Davidson, 2003; Warner, 2004; Harrow et al, 2005; Torgalsboen & Rund, 2010; Economou et al., 2011; Harrow et al, 2012). Harding et al's (1987) longitudinal study was based on 118 'patients' who were discharged from a Vermont hospital, and lived in the community. Participants within the study were prescribed Thioridazine, one of the Phenothiazines, and were then exposed to a rehabilitation programme. The findings demonstrated that 62% to 68% of participants completely recovered from schizophrenia, with 60% becoming productive, and the majority not needing to take medication after ten years. Even though the focus of this study was on the impact of medication in the process of recovery,

it did evidence the fact that people diagnosed with schizophrenia do recover. The UK's Royal College of Psychiatrists indicated that some people diagnosed with schizophrenia recover in different ways. Out of every five people diagnosed with schizophrenia, one recovers within the first five years of diagnosis; three people out of five recover with symptoms, which will sometimes become worse; and one out of five experiences symptoms on regular bases.

Harding et al. (1987) identified the following as key elements of recovery: early diagnoses, symptoms and medication management, individualised holistic care, client involvement throughout the care process, rehabilitation and psycho-education, community integration, opportunity for productive work, self-sufficiency and hope. The results of this study brought new light to mental health professionals and services alike, while improving the quality of life for individuals living with schizophrenia (Harding et al., 1987). The WHO conducted a number of studies that confirm that people diagnosed with mental illness do recover (WHO, 1979, 2009). These studies also acknowledged that recovery happens at different levels. For example, some individuals recover completely so that medication is discontinued; others are reintegrated into the community, but still have to take medication for the rest of their lives; and others feel they have recovered without complete remission of symptoms. In light of these findings and due to the fact that 50% of people diagnosed with schizophrenia do recover (Lieberman & Kopelowicz, 2002; Spaniol et al., 2002; Silverstein & Bellack, 2008), it is paramount to design recovery focused mental health services that meet the needs of those living with a mental illness within a given cultural context. The findings of Harding et al.'s (1987) study and those of the WHO (1979; 2009) concur with those of the more recent UK Schizophrenia Commission report (2012), demonstrating an impetus to collate research findings which continue to positively influence contemporary research and the design of mental health services. Following the studies that evidenced recovery from mental illness came the emphasis on the

deinstitutionalisation of services. Patients' needs were found to be unique and diverse, and not merely a case for support with remission of symptoms. For example, psychiatric hospitals, should be designed in such a way that promotes deinstitutionalisation; with the incorporation of community based services (Anthony, 1993).

For a long time patients living with mental illness had little input in their care, with professionals taking charge of all their decisions (Anthony, 1993). However, people with lived experience of mental illness have testified about their experience of recovery, consequently leading to the development of contemporary models and general assumptions of recovery; which are significant in recognising patients as having expert knowledge in their own right and the capacity to inform others of how they could best be supported during their journey of recovery from mental illness (Warne & McAndrew, 2007). Such information is useful to mental health services, and those involved in supporting patients through their recovery journey, by recognising their expertise and articulating the process in language that is accessible and meaningful to all (Warner, 2009). Before discussing issues of language around the process of recovery below are some of the examples of recovery models and the eight basic assumptions of this process.

### **1.6.2 Models of recovery from mental illness**

While the focus of recovery shifts from that of objectivity to one of subjectivity a more enlightened model of recovery continues to emerge. Contemporary models of recovery are structures or tools designed by patients based on their subjective experience of living with mental illness. Subjective experiences include instillation of hope, empowerment, development brought about by the mental illness, professional support and that which comes from significant others, and support for human rights (Warner, 2009). For example, in a study in the UK, SUs

identified 100 elements which promoted their recovery. A conceptual framework was then developed, Personal Recovery Framework (PRF), based on these subjective elements and was subsequently adapted for practice (Slade, 2009). However, in keeping with the ideology of contemporary models of recovery this can only serve as a guide to supporting the process of recovery from mental illness, as the journey is one that is unique to each individual.

#### ***1.6.2.1 Wellness Recovery Action Plan (WRAP)***

WRAP is a step by step self-supportive plan that was developed in 1997 by patients living with mental illness in the USA, who wanted to recover from the illness. The patients were supported by Dr Helen Mary Copeland, who also confessed to have benefited from using the tool (U-Tube audio, Copeland, 1995-2015). Patients using the tool take ownership of their destination, goals and desires, they develop a plan of action on daily bases, acknowledge triggers of becoming unwell and how best to cope, they also delineate early warning signs along with indicators of when things are getting out of hand. They then develop an action plan. Patients also devise a crisis plan and how they would cope after a crisis (Copeland, 1995-2015). WRAP is based on five key concepts: hope, personal responsibility, education, self-advocacy, and support (Copeland, 1995-2015).

#### ***1.6.2.2 Recovery: An Australian Perspective***

An Australian team of researchers, Andresen et al. (2003), conducted a critical study of personal narratives of psychiatric patients, from which they came up with a conceptual model of recovery, consisting of the following:

- a. Finding and maintaining hope
- b. Re-establishing a positive identity
- c. Building a meaningful life

d. Taking responsibility and control

In an autobiographical account Helen Glover reiterated her own journey of recovery from mental illness. Glover was a teacher before she was diagnosed with mental illness, however, after becoming unwell, the department of Education in Queensland did not feel able to continue her employment because she was diagnosed with a mental illness. With her optimistic attitude, she changed career and graduated as a social worker, where she did not only enjoy working with people living with mental illness, but recognised it was also an opportunity for her to recover, as she interacted with empowering professionals (Glover, 2012). As a result of her experience Glover, identified five developmental stages which she believes are evident in those in the process of recovery. Because of her experience, Glover asserts that the following are important in helping survivors regain direction of their lives (Glover, 2012, p. 8-9):

- a. From passivity to an active sense of self: where, rather than depending on others' input and initiative, the patient survivor has the energy to use her strength, abilities and initiative in the process of recovery
- b. From hopelessness and despair to hope: instead of giving up, one realises that there is a bright future ahead
- c. From others' control to personal control and responsibility: being responsible for one's actions and destiny, versus blaming others or situations
- d. From alienation to discovery: using the past to positively influence the future, or learning from past experience
- e. From disconnectedness to connectedness: social inclusion and involvement with the rest of the community, as a citizen, instead of isolating or being isolated as a result of living with mental illness.



### ***1.6.2.3 The Star Recovery***

In the UK, the Mental Health Providers Forum (MHPF) developed a tool to accomplish two purposes: to be used in implementing recovery for patients, and as a measurement of their prognosis. The outcome measurement tool was developed using recovery based academic information, as well as evidence from patients' accounts of their recovery from mental illness, and this led to the development of core areas of a recovery journey (Dickens et al., 2012; Killaspy et al, 2012). The ten core areas of the recovery journey from mental illness are: i) Managing mental health; ii) self-care; iii) living skill; iv) social networks; v) work; vi) relationships; vii) addictive behaviour; viii) responsibilities; ix) identity and self-esteem; and x) trust and hope. The service user works alongside his/her key-worker to score the level of achievement at each of the ten core areas, using the ladder of change. The ladder of change has five steps which map a person's position in the journey from being unwell to recovery, so that a patient who identifies him or herself as being in level five (in one of the core areas) indicates being much better than one on level one or two, of the same core area. Starting from the bottom to the top of the ladder an individual may be *stuck* with a problem, where they are unable to accept its existence; or they be on level two where they acknowledge that a problem exists and look and *accept help* to get it resolved. In level three one may *believe* that she or he can be an agent of change to the problem, by either doing something him or herself, or even finding help from others in an attempt to achieve their set goal(s); or move on to level four where they *learn* and put into practice different strategies to achieve their goals implement. In level five individuals identify themselves as self-reliant and feel that they can manage their problems independently. The ladder helps patients in identifying areas that need improvement and working on. Additionally, using this tool in recovery assist patients to gain confidence in talking about issues they would otherwise not be able to discuss (Mental Health Providers Forum, 2008).

Although patients were involved in the design of the tool, the Forum acknowledged that this was limited. This was also pointed out during a research seminar on the Star Recovery, where it was recommended that patients should be highly involved in the design and formulation of the recovery tool (Recovery Star Research Seminar, 2013). A survey undertaken by Killaspy et al., (2012) indicated that almost 90% of patients and close to 90% staff using the Star Recovery model stated that it is a very useful tool.

#### ***1.6.2.4 The Recovery Star modified***

The Mental Health Providers Forum (2008) conducted a pilot study amongst two groups of Black, Asian and Minority Ethnic (BAME) group, where the star recovery tool was tested to ascertain if it addressed the issues of race and culture to those who experience mental health problems. More than 80% of participants said they found the tool enjoyable, and gave them a better understanding of their intended goals. Half of the participants stated that it was difficult to read and understand the tool, mainly due to language barrier. In the first group more than 60% felt that the tool did not cover some aspects of cultural identity (possibly due to the issue of language), yet 37% of the second group felt the same. The majority of participants also indicated that most of the ten core areas of the tool were related to them (Imonioro, 2009). However, they made a few recommendations which led to the modification of the recovery tool.

The BAME group felt that issues around religion, culture, the role of the family in promoting recovery, language, additive behaviours and identity and self esteem, needed to be either modified and/or included in the tool. To clarify and promote understanding of the tool pictures

were created for each of the core areas and the steps of the ladder. Secondly, the area of language has been included in a number of core areas. For example under ‘Living Skills’, patients are to indicate that they are attending literacy classes as a way of improving their English language. Excessive hand washing and self harm were incorporated under the core area of addictive behaviours. In the modified recovery model, patients can now score and talk about their ‘identity and self-esteem’ in relation to how they feel about their culture, spirituality and religious beliefs (Mizock et al., 2012)

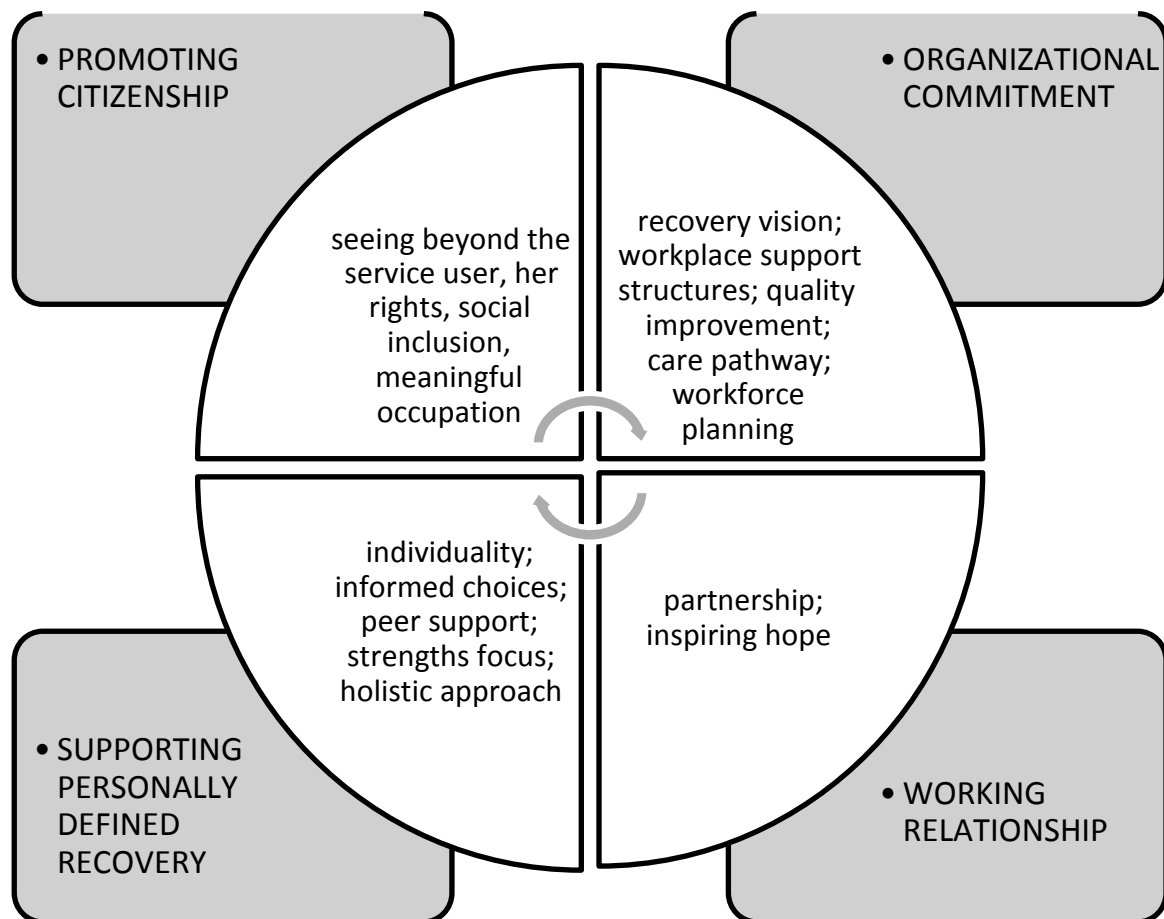
The last step of the ladder, ‘self-reliance’ has been modified, following participants’ feedback that its definition did not reflect a similar meaning to them. Most BAME felt that self-reliance is defined within the parameters of social relationships, and not as an autonomous individual. Consequently, additional statements to include support from family and significant others have now been added, to reflect the communal support from various social groups.

#### ***1.6.2.5 A comprehensive model of recovery***

Patients indicated that one of the influences of their recovery from mental illness was the way mental health services are designed, and the support given to them by professionals. Consequently, recovery lead services have been identified as enhancers of recovery, and this is predominately reflected in the organisations’ practise documents, such as the policies and procedures, and philosophies (Deegen, 1988; Anthony, 1993; Glover, 2012).

In an attempt to come up with a unified international conceptual framework, Le Boutillier et al., (2011) reviewed 30 international documents of recovery-focused services. Thematic analysis was used to identify commonly emerging themes, and these were merged into sixteen dominant themes. These were then grouped into four domains applicable to practice.

Figure 2 below summarises the conceptual framework that came out of this study. While these were taken from developed countries (England, Scotland, USA, Denmark, New Zealand and the Republic of Ireland) the conceptual framework could be used as a source of reference and to develop further research (Le Boutillier et al., 2011).



*Figure 2 A recovery focused service by SCN, adopted form Le Boutillier et al., 2011*

#### ***1.6.2.6 Basic assumptions of recovery from mental illness, adopted from Anthony (1993)***

Recovery can occur with, or without professionals. As such, professionals must be aware that patients are the leaders in their journey of recovery. This becomes important in the formulation of service user centred care plans, as opposed to a 'one size fits all' (South London and Maudsley NHS Foundation Trust and South West London and St George's Mental Health NHS Trust, 2010). Some of the important facets of recovery include the following;

- Patients have acknowledged the importance of support given by others during the journey of recovery. Meaning that recovery was promoted by encouragement from those who believed in them.
- Recovery from mental illness is not determined by its cause, whether physiological or psychological. Recovery can still occur even if the physical condition is present or becomes worse.
- The reoccurrence of symptoms of mental illness is not an indication that an individual is not recovering.
- Recovery is associated with a reduced frequency and duration of symptoms. So that even if symptoms reoccur, their interference to the service user's daily life is much less than the previous reoccurrence.
- The recovery journey is not a straightforward one, even to the individual who experiences it. So that while there are episodes of rapid growth and development, insight into progress; there may also be hindrances, periods of confusion, lack of insight, and possible growth retardation.
- The loss of one's ability to perform certain task and the loss of self-esteem, following being mentally unwell are the two issues which hinders the process of recovery. It is therefore important not to rely on the absence of symptoms, as measure for one's

recovery. Patients play a central role in informing others of their position in the recovery journey.

- Those who have recovered from mental illness must have had a real experience of the illness, and not just mimic being mentally unwell.

#### ***1.6.2.7 The Medical Model and Recovery from Mental Illness***

Despite attempts to make the voice of mental health experts louder by promoting and implementing the recovery values, there remains a constant tension between the medical perspective of mental illness and the use of the recovery model (Roberts & Wolfson, 2004). This is due to their different values. As already discussed, recovery is subjectively defined by those who experience the mental illness. On the contrary, evidence and objectivity is associated with the presence of illness, diseases and treatment. One of the distinctive features of these paradigms is that recovery focuses on the patient as an expert, because of his or her experience of illness, so that he or she becomes the central tenet of interest; while the medical perspective focuses on the disorder or illness, viewing health professionals and their instruments as experts and the main source of information about the illness, management and treatment; with limited consideration of patient contribution (Ralph et al, 2002; May, 2004; Roberts & Wolfson, 2004). A number of authors have highlighted significant distinguishing issues between the two paradigms, attributing this to their use of language (Ralph et al., 2002; Allott et al., 2003; May, 2004). A discussion on some of the contrasting phrasing delineated by the authors above is discussed below.

The recovery model perceives illness as a distressing experience, while the medical model focuses on psychopathology; a scientific study of mental disorders. The experts' account of his or her life is key to understanding the illness in the recovery model, yet pathography (the study

of one's life and the influence of the illness in that life) enhance others' understanding of the illness. The medical model gives a label of a 'diagnosis' to the illness, while recovery describes the illness in terms of the experts' 'personal meaning.' Recovery uses terms such as choice, growth and discovery; in contrast to the use of compliance with treatment in the medical domain.

Although similar to a certain extent, Shean (2010) introduced another perspective to the perspective of schizophrenia and recovery, based on the causes of schizophrenia. Within the biomedical model schizophrenia is said to be caused by genetic defects which results in biochemical changes to the brain; so that pharmaceutical interventions is paramount to reversing the defects. On the contrary, the focus of the psychosocial model advocates that schizophrenia is triggered by interactions in society and, along with the genetic influences, medication is unable to address the causes of the illness. The diathesis-stress model addresses the weaknesses of each of the two former models; integrating in the bio-psychosocial contributions to the triggers of schizophrenia to develop effective strategies that enhance recovery from schizophrenia (Shean, 2010). The Schizophrenia Patient Outcomes Research Team (PORT) developed evidence based bio-psychological guidelines for promoting recovery of people living with schizophrenia; these consist of 16 psychopharmacological treatments and 8 psychosocial interventions (Kreyenbuhl et al., 2010).

The outcomes of living with mental illness leads to transformation in the recovery model, yet in the medical perspective talks about returning to normal function. The focus of this study is the recovery perspective; where contributions from people living with mental illness is highly valued, and the intention is to find new insight into the lived experience of women diagnosed

with schizophrenia by attentively listening to their biographies, and interpreting them in order to develop supportive strategies which will be congruent to their needs.

### **1.6.3 The place of language in the recovery process**

Living with or having being diagnosed with mental illness comes with a number of negative emotional and/or psychological impact, with a number of people stating that they experience low mood and self-esteem, discrimination, hopelessness, and stigmatization (Ralph et al., 2002; Saks, 2002; Allott et al., 2003; May, 2004). Not only does this come from being labelled by others around them, but is also the result of the distressful experience of hearing voices, mostly negative and conflicting with their will and or desires (Deegan, 1996; Knight, 2003). As a result, the use of language is critical when communicating with people who are recovering from, or living with, mental illness, (Oaks, 2012). The use of medical terminology is particularly difficult, not least the diagnostic labels which are used and subsequently initiate some of the above problems.

David Oaks is the founder of Mind Freedom International (MFI), which was launched in 1976. Being a survivor of schizophrenia and bipolar disorder, he was an executive director of the MFI until 2013. In May, 2012, members of the MFI assembled in front of the American Psychiatric Association annual meeting, where they engaged in 'Mass Label Rip.' During this time the psychiatric survivors (this is how they prefer to be called) held up papers on which various diagnoses of mental illness were written. They then ripped them up to demonstrate that they are not the diagnosis, but human beings. They also stated that the medication prescribed in the treatment of mental illness is toxic and should therefore not be prescribed to human beings. The psychiatric survivors also emphasised that the medication did not help them solve their problems, but made them sleep or temporarily ignore the challenges they were faced with ([www.mindfreedom.org/apa](http://www.mindfreedom.org/apa), 20/01/2015).



The significance of the use of language should not be underestimated. The use of the phrase “mental illness” has a medical connotation, giving the impression that because an individual has an ‘illness’ it is the doctor who holds the power of providing a resolution or ‘cure.’ Yet, from the experience of those diagnosed with mental illness, recovery has been found to take place with or without medication or professional input (Torgalsboen & Rund, 2010; Economou et al., 2011; Harrow et al, 2012). Oaks (2012) assert that the phrase ‘mental illness’ or mentally ill’ must be abolished, and replaced by phrases such as: *people with lived experience; lived expertise of mental illness; users of mental health services; people living with mental illness; person diagnosed with psychiatric disorder, user of mental health services, person diagnosed with a mental disorder, person labeled with a psychosocial disability, and psychiatric survivors* (Oaks, 2012, p.1). However, this raises another area of debate, that of how to refer to people living with mental illness.

While those living with mental illness are referred to as clients, SUs, consumers, survivors, to name but a few, it has been suggested that people living with mental illness want to be called patients rather than clients, because being referred to as clients erodes professional standards (Deber et al., 2005). The word client originates from Latin, meaning one who is being protected by another, again patients reinforcing power differential. Others do not want to be referred to as patients because this also has a connotation of dependency and passivity (Calloway et al., 2001), as it implies professionals are acting upon users of mental health services, while they ‘passively’ receive the care offered by ‘experts’ (Deber et al., 2005). In this study the following phrase “patients” will be used as it is generally acceptable in Swaziland.

#### ***1.6.3.1 Learning lessons on recovery from developing countries (5)***

The outcomes of recovery from mental illness, including schizophrenia, are said to be much better in developing countries than in the developed world (Sullivan, 1994; Anders, 2003; Warner, 2004; Gureje et al., 2007; Cohen et al., 2008; Warner, 2009; Myers, 2010; Shean, 2010). This has been evidenced through the International Pilot Study of Schizophrenia (IPSS) (WHO, 1979), comparing the long term outcome of 1 202 patients living with schizophrenia in developing and developed countries. Out of the nine countries involved in the study, two were third world countries; India and Nigeria (Sartorius et al., 1974). This initial study was criticised for recruiting in-patient participants only, implying that their findings were not representative of a population diagnosed with schizophrenia. Other international follow up longitudinal studies of 15 and 25 years included ten countries with diverse cultural communities (Harrison et al., 2001). Patients living with schizophrenia in developing countries recovered quicker, within two years, than their counterparts in the developed world; with the best outcomes from Chennai in India, where two thirds of the participants had no psychotic symptoms for up to thirty years (Harrison et al., 2001; Myers, 2010; Shean, 2010).

Other authors (Sullivan, 1994; Anders, 2003; Myers, 2010) suggest that enhanced recovery in developing countries is due to the use of non-invasive strategies in managing mental illness. Countries such as China and India use less medication in managing those affected by mental illness; rather they engage all community members in utilising the community healing methods. As a result it is thought that recovery from mental illness is a quicker process as people are integrated into the community sooner (Sullivan, 1994; Anders, 2003; Myers, 2010). From a personal perspective I believe this mirrors the situation in Swaziland, where community healers are involved at the initial onset of illness. However, those who fail to respond to community

interventions are referred to the SNPH at a later stage of illness and therefore the importance of early intervention is compromised.

While the reason(s) for better outcome in recovery from mental illness in developing countries is not known, some authors suggest that living in the third world, such as Africa, is less stressful than living in developed countries (Sullivan, 1994; Gureje et al., 2007). Globalisation and disintegration of social support structures in developing countries is a possible cause of the prolonged recovery rate within these societies. For example working in most developed countries requires employees to acquire highly competitive knowledge and skills, while such skills might not necessarily be required to earn an income in developing countries, most of which are agriculturally based. Socio-cultural activities like the healing ceremonies done in third world countries have been thought to be facilitators of recovery, as people feel integrated into their community, and are therefore likely to experience less stigmatisation (Shean, 2010). This implies that people living with schizophrenia in developed countries are more likely to express work related stress which could compromise their rate of recovery, compared to their counterparts in developing countries.

The evidence presented in this chapter has established the need for providing appropriate support to those who experience mental illness, and for exploring this in the context of an African country, where little is known. It would appear that contemporary models of recovery that acknowledge the expertise of the person living with the illness are advantageous over the more traditional medical model. Early intervention, collaboration and integration back into the community have been identified as key factors in the recovery process however, these can sometimes be compromised by societal and cultural influences as well as lack of resources. In

addition, the lack of research regarding recovery having a gender bias prompts further study if mental health services are to be sensitive to the needs of those using them.

### **1.7 Motivation of this study**

After graduating as a general nurse, my passion to specialise in mental health nursing was fuelled by the desire to provide holistic nursing care. However, it is difficult for health professionals to provide holistic care without knowing what specific health and social needs people have. It has been suggested that professionals need to work together with patients, through collaboration and partnership, in order to understand and meet their needs (Warne & McAndrew, 2009; Wojnar & Swanson et al., 2007). A phenomenological approach helps researchers to engage in holistic investigation, which leads to better understanding of participants' experiences (Streubert & Carpenter, 2007). As a Swazi woman, living and practicing as a qualified mental health nurse in the UK, I became curious to understand how Swazi women define recovery from schizophrenia, and what hinders and or promotes this process. I purposively selected Swazi women living with the diagnosis of schizophrenia from the outpatients' department at the SNPH, as not only did these women share a diagnosis, they were all identified as recovering from schizophrenia, evidenced by living in the community and I shared their ethnic origin.

During a presentation of my study to PhD students (which included, but was not limited to nurses, physiotherapists, and occupational therapists) I was questioned about why I was undertaking research focusing on people living with mental illness, as the information they would give me might not be authentic due to their illness. I was worried by such comments, and realized the importance of mental health professionals implementing de-stigmatization

strategies to colleagues and society, regarding people living with mental illness, and specifically those diagnosed with schizophrenia.

In response to my colleagues I explained how being diagnosed with schizophrenia has a negative impact on one's self esteem, and by creating an opportunity for people to talk about their experiences and be heard, is a primary mode of restoring a lost sense of self-worth and value (Borg & Davidson (2008). The importance of being heard was emphasised by another one of my colleagues, (a nurse) during discussion of our PhD research projects. After informing her about my study, her facial expression was one of disbelief, and she stated:

*“Do people diagnosed with schizophrenia actually recover, even from other forms of mental illness?.....Having been practising as a nurse for over 25 years now, I have never heard about this!.....If I as nurse, am not aware of such information, how likely is it that the general public will know. I do suffer from severe depression, and never thought I would recover.”*

I then told her about a few individuals who have recovered from schizophrenia, including the story of one of relatives (discussed earlier within this chapter). This conversation lead to an escalated passion and interest in my area of study, as my colleague appeared enthusiastic stating *“I will definitely come to your research presentation in May, 2015.”* For me, one of the issues that stood out during the discussion was my colleague's repeated reference to how she feels that *“professional having no time to listen to patients who live with mental illness, but would rather bombard me [my colleague] with medication because they say I [colleague] need it.”* While medication assists patients to temporarily alleviate presenting symptoms of an illness, there is a plethora of evidence to suggest that being listened too is therapeutic in its own way (McAndrew et al., 2014). In light of this it was important that I chose a methodology that would ensure the participants voice was fore grounded throughout the study as this would also be in keeping with the ethos of contemporary models of recovery. A detailed discussed of the methodology of this study can be found in chapters four and five.

## **1.8 Aim of the study**

The aim of this study was to understand the process of recovery from the perspective of Swazi women living with schizophrenia. To date there is no documented evidence to reflect how mental health services in Swaziland promote recovery for those people diagnosed with schizophrenia. In trying to address this gap, the study explored how Swazi women diagnosed with schizophrenia perceive recovery, and what, for them, has hindered and/or promoted this process. It is anticipated that this study will add to a developing body of knowledge relating to recovery from the Sub-Saharan African perspective, and will hopefully influence the development of user led mental health services in Swaziland.

## **1.9 Study Objectives**

- To gain an understanding of the meaning of recovery from schizophrenia as perceived by Swazi women living with this mental illness.
- To gain an understanding of the perceptions and experiences of recovery from schizophrenia, as portrayed by Swazi women
- Identify issues that promote and/or hinder recovery
- Add to the limited body of knowledge regarding the experiences and needs of women living with schizophrenia in Swaziland.
- Recommend how mental health services at SNPH could effectively meet the needs of patients to promote recovery for women diagnosed with schizophrenia.

## **1.10 Structure of the thesis**

This thesis is arranged in seven chapters. A summary of each chapter can be found below.

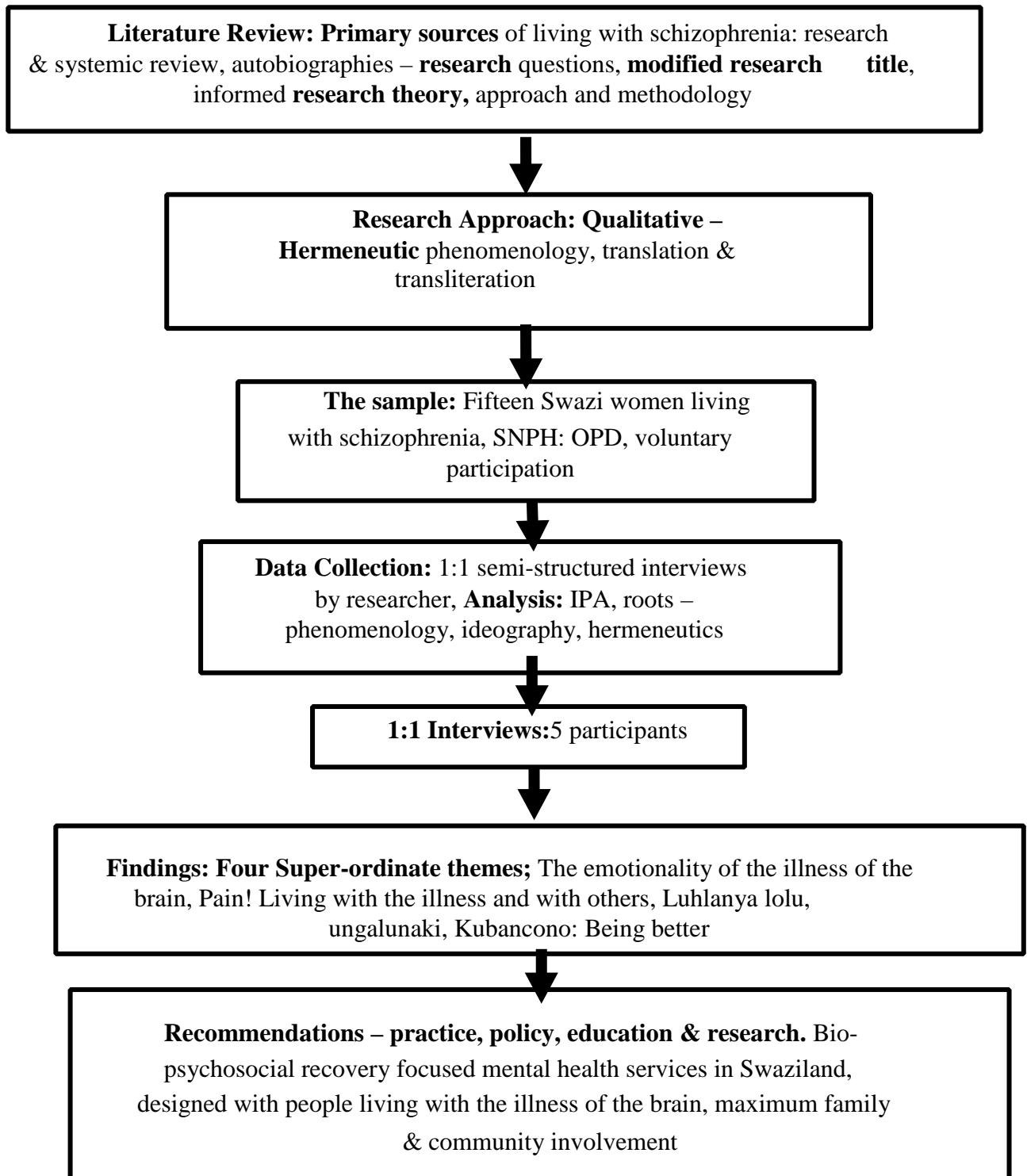
Within the body of this document I have interspersed text with relevant reflexive notes from my diary, to help the reader gain more insight into the discussions within this thesis. Besides

writing the headings and subheadings in bold, within the main document I have also written in bold those words and/ or phrases which I feel are worth noting. A conclusion is located at the end of each chapter. This delineates a summary of discussed issues, and then draws the reader's attention to the forthcoming chapter.

**In this chapter, Chapter one** the context of the study and justification of the importance of doing this research has been identified. Brief information on Swaziland and the health system was given followed by general information on schizophrenia, cost implication for treating this illness and the phenomenon of recovery was discussed. Because recovery from schizophrenia has been associated with de-institutionalisation (Shean, 2010), a discussion on this terminology and its antonym (institutionalisation) was incorporated within this chapter. My motivation of conducting this study was articulated, along with issues around language. The purpose of **chapter two** is to review the literature, that is research studies undertaken with people living with schizophrenia. The significant of this chapter is that it highlights the knowledge gap of a Swazi perception of recovery from schizophrenia, and therefore underpins the need for conducting this study. The literature review inspired the formulation of the research questions, modification of the research topic, and the theoretical approach which guide this research. **Chapter three** discusses the theoretical perspective and the methods used in conducting of this study, along with my rationale for choosing a qualitative phenomenological, design which took a hermeneutic approach in conducting this research. The theoretical approach informed the steps undertaken during data collection and analysis; these steps are delineated within this chapter. I have included **chapter four** to deliberate on issues around translation and transliteration, because this study was conducted in two languages (siSwati and English). Within this chapter I described strategies to ensure authenticity of the findings, which could be compromised during translation and analysis of participants' interviews. A detailed description

of the findings is described in **Chapter five**. This contains participants' quotation from their narration to evidence the source of the findings. Findings are clusters into subordinate and super-ordinate themes emanating from participants' stories. Swazi women's perceptions, experiences of living with schizophrenia, and recovering from it is discussed in **chapter six**, where these findings are compared and contrasted with those of other research studies (as discussed in chapter 2). The findings are discussed within the parameters of: the family, community and the SNPH. **Chapter seven** entails the closing discussion of this study; conclusion and recommendation. Within this chapter I discuss my experience of using hermeneutic phenomenology, and IPA within an African socio-cultural context, and make recommendations to other researchers. New knowledge emanating from this study is enumerated. I then discuss the implications and recommendations of the findings and how these could be used to inform clinical practice, research, education and policy development. Figure 3 below outlines a summary of the structure used within the thesis.





*Figure 3 The Research Structure*

### **1.11 Conclusion**

While there is evidence that the western world has engaged people living with mental illness in designing recovery models (Allott et al., 2003; Paquette & Navarro, 2005; Slade, 2009) this is not apparent in third world countries, such as Swaziland. Findings from this study will add to the very limited existing body of knowledge and hopefully lead to the development of a Swazi based recovery model which could be adopted and used within other African sociocultural contexts. In the next chapter, Chapter 2, the literature is reviewed and the perceptions and experiences of recovery from mental illness and schizophrenia from studies undertaken in other countries are critically discussed, however, these are mainly from the western world.

## **Chapter 2**

### **Literature review**

#### **2.1 Introduction**

The first section of the previous chapter described an overview of the context of this study; a brief outline of the country and general health issues in Swaziland. This was followed by general information relating to schizophrenia and recovery, paying particular attention to models of the recovery process. As indicated in the first chapter, one of the most important aspects about the models of recovery is that they were designed with, and/or by people living with mental illness. By listening to SUs and gaining a better understanding of their experiences of living with mental illness and recovering from it, researchers and practitioners will be better placed to offer appropriate sensitive care.

This chapter discusses the available evidence regarding patients' accounts of their perceptions of recovery and living with schizophrenia. Some of the common approaches in conducting a literature review include: traditional or narrative review; systematic literature review; meta-analysis and meta-synthesis (Cronin et al., 2008). In order to identify existing research evidence of the lived experiences of people living with schizophrenia and to bring to light the rationale for conducting this study, I chose to use the narrative approach for presenting my literature review. In turn, this approach influenced the formulation of the research questions, enabled me to refine the research topic and choose a theoretical approach which would best guide this research (Onwuegbuzie et al., 2012).

When conducting a literature review it is important to carry out a robust search for previous research undertaken (Holloway, 1996). A thorough literature search is important in establishing what other researchers have found in relation to the topic under investigation. This enables the researcher to avoid unnecessary duplication of studies which have already been done, giving justification of how the proposed study will add to a body knowledge (Holloway, 1996; Rowley & Slack, 2004, Silverman, 2010; Onwuegbuzie et al., 2012). On completion of reviewing the available literature, the researcher should be confident in the uniqueness of the study (Rowley & Slack, 2004). Conducting a thorough literature review also helps the researcher to identify, compare and select research methods that might be relevant to his/her study, as well as providing a backdrop for discussing the findings in light of what is already known and that which remains unknown (Rowley & Slack, 2004).

This chapter is divided into five main sections. The first is an account of the search strategy used to retrieve research articles for the review. Section two is a critical review of research based articles on peoples' perceptions and experience of living with schizophrenia/mental illness, and how they described their recovery process. Autobiographies of four people living with schizophrenia are discussed in section three, followed by the development of the research question and the conclusion is the last part of this chapter.

## **2.2 Search Strategy for Research Articles**

PsycInfo, Web of knowledge, Intranurse, Scopus, CINAHL, Academic Search Premier and Medline data base were used to electronically search for articles on the perceptions of recovery from schizophrenia from people diagnosed with this illness. Due to the fact that the word 'recovery' could have a different meaning in siSwati than it does in English, the phrase 'feeling better' was also used when conducting the search. The following groups of words were used

during my search: (1) Schizophrenia, recovery, perceptions, women, Africa; (2) Schizophrenia, “feeling better,” perceptions, women, Africa (3) schizophrenia, recovery, perceptions, women; (4) schizophrenia, recovery, perceptions, Africa; (5) schizophrenia, recovery, perceptions; (6) schizophrenia and “feeling better.” Also, the words perception, experience, psychosis, schizophrenia, and mental illness were used interchangeably.

### **2.2.1 Inclusion and exclusion criteria**

In order to promote transparency and clear understanding of the type of research articles used in this literature review, I have included the inclusion and exclusion criteria I used to keep my search focused. For example, there was a high volume of papers focusing on schizophrenia, therefore by stipulating research on recovery carried out in the last 20 years (1994 to 2014) as part of my inclusion criteria I was able to narrow my search and keep it focused to my chosen topic. Older papers that only focused on schizophrenia as a mental illness were eliminated. This reduced the volume of papers included in the review and prevented me wasting time reading irrelevant studies (Carnwell & Daly, 2001).

#### ***2.2.1.1 The inclusion criteria***

- i) Research articles focusing on the meaning of recovery as described by people living with schizophrenia/mental illness. During the search it was noted that there were also relevant articles which used ‘recovery from mental illnesses/psychosis as opposed to ‘recovery from schizophrenia.’ As a result, research papers on recovery from mental illness/psychosis were also included.
- ii) Research articles published within the past 20 years (1994 to 2014): as more attention has been given to the concept of recovery during this period (Borg & Davidson (2008).
- iii) Research based papers and systematic reviews were included as they are a primary source of evidence based information, as opposed to secondary sources (for example

books) which generally have reconstructed information that has been cited by the authors rather than from the original source (Silverman, 2010).

- iv) Peer reviewed papers: because they are scrutinized by experts in mental health and/or specifically on the subject of recovery. Peer reviewed papers published in professional journals as these are more likely to have significance, validity, clarity and originality.
- v) Stories or autobiographies because they are authentic accounts of lived experiences, and therefore serve as a good source of information pertinent to this study.

#### **2.2.1.2 Exclusion criteria**

- A. Literature reviews that are not research based.
- B. Perceptions of recovery from others, for example health professionals and/or family members. Including these papers could have either widened the scope of this study, or lead to divergence from the intended focus.
- C. Editorial papers, as these often contain secondary information and opinion pieces from various people, such that the origins of such information may be questionable.

After applying the inclusion and exclusion criteria to the search, 41 articles were located using each of the search engines identified above. Five further research articles were found through citation referencing, one of which focused on women, and their perceptions of recovery from mental illness. Hence, a total of 46 articles, on SUs' perceptions of recovery from mental illness, were reviewed.

### **2.3 Review of the Identified Literature**

All 46 relevant research articles were printed and read in detail. A table that demonstrates how I summarised the main aspects of some of the research articles namely: aim of the study, methodology, recruitment/participants, data collection, data analysis and findings, was

formulated, refer to appendix A. Formulating the table gave me a general, summative overview of all the articles, and made it easy to compare and contrast the aims, research methods, participants, and findings of each study. As such, this review will be presented within the parameters of the headings above. Within the 46 studies reviewed, 36 were qualitative studies, five quantitative and five used mixed methods. This is shown in table 3 below.

**Table 3 Research studies and their methods**

<b>Methodology</b>	<b>Author(s)</b>	<b>N=</b>
<b>Qualitative</b>	Young & Ensing (1999); Pejler et al., (1999); Chernomas et al. (2000); Smith (2000); Ridgway (2001); Meddings & Perkins (2002); Spaniol et al. (2002); Torgalsboen & Rund (2002); Andersen, 2003; Tooth et al. (2003); Knight et al., (2003); Jenkins & Carpenter-Song (2005); Mancini et al. (2005); Bradshaw et al. (2006); Bradshaw et al., (2007); Noiseux & Ricard (2008); Pitt et al. (2007); Borg & Davidson (2008); Ng et al., (2008); NHS Health Scotland, 2008; Noh et al. (2008); Wisdom et al. (2008); Armour et al. (2009); Piat et al. (2009); Romano (2010); McKay (2010); Mezey et al. (2010); Chadwick, S.L. (2011); Kalathil et al. (2011); Lam et al. (2011); Patterson et al. (2011); Manuel et al. (2012); Ng et al. (2012); Thara (2012); Bromley et al. (2013)	<b>36</b>
<b>Quantitative</b>	Marshall et al. (2009); Chiba et al. (2010); Albert et al. (2011); Roe et al., (2011); Beck et al., (2012)	<b>5</b>
<b>Mixed methods</b>	Hoffmann and Kupper (2002); Jenkins et al. (2005); Lysaker et al. (2010); Torgalsboen & Rund (2010); Wood et al. (2013)	<b>5</b>
<b>Total no of Research of Papers</b>		<b>46</b>

### **2.3.1 Purpose/Aim**

All the reviewed articles have a clearly written purpose. The general aim of the qualitative studies was to understand the lived experiences and/or perceptions of recovery from individuals living with severe mental illness, mainly schizophrenia. It is significant to note that the researchers in all 46 articles appeared to have paid equal attention in attempting to understand SUs' lived experiences of recovery from both schizophrenia and mental illness. Whilst schizophrenia and mental illness were key words used during my literature search, it is the former that this research is mainly concerned with. However, the analysis below reflects that more than half (19) of the reviewed qualitative studies aimed at investigating SUs' experience of recovery from mental illness, while the remainder, (17) focus on SUs' experience of recovery from schizophrenia.



### **2.3.2 Schizophrenia and recovery**

While it could be argued that my literature review should have only included studies focusing on schizophrenia and recovery, rather than to include studies on mental illness and recovery, from my knowledge as a Swazi and experience as a mental health nurse, there is no siSwati name for schizophrenia. In fact, the classifications of mental illness as evident from a western medical perspective is different to how mental illnesses are classified in Swaziland, where mental illness of any type is usually referred to as the ‘illness of the brain.’ A detailed discussion around these issues follows later on within this thesis. Therefore, including mental illness and recovery was relevant, as it allowed a wider analysis of studies on how people in various cultural settings recover from mental illness. Consequently, the words schizophrenia and mental illness will be used interchangeable within this thesis.

Of the 46 studies reviewed, 20 studies specifically focused on schizophrenia and recovery: Pejler (1999); Chernomas et al. (2000); Hoffmann & Kupper (2002); Meddings & Perkins (2002); Spaniol et al. (2002); Torgalsboen & Rund (2002); Jenkins & Carpenter-song (2005); Tooth et al. (2003); Jenkins et al. (2005); Ng et al. (2008); Noh et al. (2008); Noiseux & Ricard (2008); Chiba et al. (2010); Lysaker et al. (2010); Romano et al. (2010); Torgalsboen & Rund (2010); Patterson et al. (2011); Roe et al. (2011); Ng et al. (2012); Thara (2012).

Sixteen of the studies above focused on the perceptions of recovery from people living with schizophrenia, their specific areas of focus being: (1) recovering from hospital to a home setting (Pejler, 1999); (2) women and schizophrenia, (Chernomas et al., 2000); (3) facilitators of recovery ( Hoffmann & Kupper, 2002); (4) themes of recovery (Spaniol et al., 2002); (5) lessons learned from three studies of recovery from schizophrenia (Torgalsboen & Rund,

2002); (6) experience of recovery (Jenkins & Carpenter-Song, 2005); (7) enhances and hindrances of recovery (Tooth et al., 2003); (8) antipsychotics and the subjective process of improvement (Jenkins et al., 2005); (9) recovery from schizophrenia as seen by those who had been living with the illness for a longtime, (Ng et al., 2008); (10) reliability and validity of the Japanese version of the recovery assessment scale for people with chronic mental illness (Chiba et al., 2010); (11) personal narratives and recovery from schizophrenia (Lysaker et al., 2010); (12) the process of recovery at the initial diagnoses (Romano et al., 2010); (13) maintenance of recovery from schizophrenia (Torgalsboen & Rund, 2010); (14) the relation between objective and subjective domains of recovery among persons with schizophrenia-related disorders (Roe et al., 2011); (15) recovering from hallucinations of people with schizophrenia in Hong Kong (Ng et al., 2012); and (16) consumer perceptions of recover, an Indian perspective (Thara, 2012).

The other four studies explored the meaning of recovery from schizophrenia as perceived by users of mental health services and other groups of people (Meddings & Perkins, 2002; Noiseux & Ricard, 2008; Noh et al., 2008; Patterson et al., 2011). One of these studies examined recovery as perceived by people with schizophrenia, family members and health professionals (Noiseux & Ricard, 2008), and one explored what 'getting better' means to staff and users of a rehabilitation service (Meddings & Perkins, 2002). The aim of the study conducted by Patterson et al. (2011) was to discover if the perception of recovery differed between participants receiving treatment as part of a compulsory order, and those that were not. Noh et al. (2008) focused on schizophrenia, and the nature of hope and recovery.

### **2.3.3 Mental Illness and Recovery**

In total 23 studies aimed at exploring the lived experiences of people diagnosed with severe mental illnesses or psychosis in general, and not specifically schizophrenia. These were conducted by: Young & Ensing (1999); Smith (2000); Ridgway (2001); Mancini et al. (2005); Bradshaw et al. (2006); Bradshaw et al. (2007); Pitt et al. (2007); Armour et al. (2009); Borg & Davidson (2008); Wisdom et al. (2008); Marshall et al. (2008); Piat et al. (2009); McKay (2010); Mezey (2010); Albert et al. (2011); Chadwick (2011); Kalathil et al. (2011); Lam et al. (2011); Leamy et al. (2011); Beck et al. (2012); Manuel et al. (2012); Wood et al. (2012); Bromley et al. (2013).

The specific focus of the studies were as follows: (1) consumers' meaning of recovery (Young & Ensing, 1999); (2) elements of recovery, (Smith, 2000); (3) theories of facilitators and hindrances (Mancini et al., 2005); (4) service user-led perception of recovery: patients experiences of recovery from mental illness during the initial phase (Bradshaw et al., 2006); (5) consumers' experience of recovery from severe mental illness (Bradshaw et al., 2007); (6) user-led description of recovery from psychosis (Pitt et al., 2007); (7) recovery from mental illness, African America consumer's perspective (Armour et al., 2009); (8) consumers' description of recovery from mental illness (Piat et al., 2009); (9) within the person's life (Borg & Davidson, 2008); (10) identity and recovery (Wisdom et al., 2008); (11) patients' perceptions of receiving recovery focused services (Marshall et al., 2008); (12) meaning of recovery in forensic patients (Mezey, 2010); (13) predictors of recovery from psychosis (Albert et al., 2011); (14) predictors of good recovery outcome after psychosis (Chadwick, 2011); (15) consumers' meaning of recovery from psychosis (Lam et al., 2011); (16)

subjective judgments of perceived recovery from psychosis (Beck et al., 2012); (17) patients' perceptions of recovery (Wood et al., 2012); and (18) community experience of recovery from patients diagnosed with serious mental illness (Bromley et al., 2013). Bradshaw et al. (2006 & 2007) emanated from the same study. The areas of focus for the other four studies are identified in the paragraphs below, because, together with the study undertaken by Chernomas et al. (2000), they specifically explored the experience of recovery from mental illness from the perspectives of women.

#### **2.3.4 Schizophrenia, Recovery and Women**

It is interesting to note that out of the 42 studies on service user's perceptions of recovery from mental illness/psychosis/schizophrenia, only five of these specifically focused on the experiences of women (Chernomas et al., 2000; Ridgway, 2001; Manuel et al., 2010; McKay, 2010; Kalathil et al., 2011), evidencing that very little research on schizophrenia and women has been undertaken. However, all five studies were conducted with women living in developed countries, even though the study by Kalathil et al., (2011) involved women of ethnic minority (African, South Asia, and African-Caribbean) these were women living in developed countries.

The purpose of the studies focusing on women and recovery is as follows: perspectives of women living with schizophrenia (Chernomas et al., 2000); learning from first person narratives (Ridgway, 2001); women's experience of living with mental illness (McKay, 2010); and perceptions of women with severe mental illness on the transition from hospital to the community (Manuel et al., 2010). Although the study undertaken by Chernomas et al., (2000) focused on schizophrenia, the issues of recovery only emerge during the discussion of the findings, rather than it being the main focus.

#### **2.3.5 Locations of Studies**

Out of the 36 studies conducted on patients' perceptions of recovery from

schizophrenia/mental illness, all but four (Ng et al., 2000; Ng et al., 2012; Lam et al., 2011; Thara, 2012), were conducted in developed countries (America, Australia, Canada, New Zealand, Norway and the United Kingdom). Three of the studies carried out in developing countries were undertaken in China (Ng et al., 2000; Ng et al., 2012; Lam et al., 2011), with the fourth being carried out in India (Thara, 2012). The general aim of these studies was to explore peoples' definitions and experiences of recovery from mental illness.

### **2.3.6 Methodology**

In view of the aims of each study, it was anticipated that a qualitative research design would be more applicable in answering the nature of the question/s being asked; the patients' lived experiences of recovery from schizophrenia/mental illness. Perhaps this is evident in the number of studies which used qualitative approach over quantitative. Out of the 46 research paper retrieved, 36 studies used qualitative methods, with almost half (16) making their approach explicit. Grounded theory was indicated to have been used in five studies (Young & Ensing, 1999; Mancini et al., 2005; Noiseux & Ricard, 2008; Ramano et al., 2010; Bromley et al., 2013). Jenkins and Carpenter-Song (2005) used ethnographic observation. Five studies either used narrative or thematic analysis (Pejlert et al., 1999; Ridgway, 2001; Tooth et al., 2003; Noh et al, 2008; McKay, 2010). Out of the five studies which indicated using a phenomenological perspective, three specified using a hermeneutic perspective (Bradshaw et al., 2006; Borg & Davidson, 2008; Armour, 2009), and two used Interpretive Phenomenological Analysis (IPA) (Knight et al., 2005; Pitt et al., 2007).

Hoffmann and Kupper (2002); Marshall et al. (2009); Chiba et al. (2010); Albert et al. (2011); Beck et al. (2012); Calvelt et al. (2012); and Roe et al. (2012) utilised a quantitative research

design within their studies of SUs' experience of recovery from severe mental illness. Although the studies undertaken by Hoffmann & Kupper (2002); Marshall et al., (2009); and Lysaker et al. (2010) do not actually state the research methods used. However, the large number of participants (274, 103, and 255 respectively), and the use of numerical statistical analysis of findings, are suggestive of quantitative methods being used in these studies (Gerrish & Lacey, 2010; Silverman, 2011). In addition, the use of variables, a number of instruments of measurement (PANSS, GAF, DSA-M, NOSE-30, IPC scales), and the detailed numerical comparison for participants, reflects the quantitative design inherent in these studies. Jenkins et al. (2005); Lysaker et al. (2010); Torgalsboen & Rund (2010); and Wood et al. (2013) used a mixed method approach. In employing mixed methods the above researchers had the advantage of minimising the limitations of each method, by being able to triangulate the data (Barbour, 1999).

### **2.3.7 Participants and recruitment**

In a significant number of studies participants identified themselves as recovering, either from schizophrenia or severe mental illness (Chernomas et al. 2000; Smith, 2000; Tooth, 2003; Mancini et al., 2005; Noiseux & Ricard, 2008; Borg & Davidson, 2008; Piat et al. 2009; McKay, 2010; Romano et al., 2010; Bromley et al., 2013). Although not specified, in the other studies it appears that the participants had the autonomy to be involved if they considered themselves as recovering from a mental illness. According to Opie, (1992) volunteers, or those who identify themselves as meeting research criteria, which would enable them to participate, is a very important strategy in recruiting participants, as such participants are likely to be more open and share their lived experiences.

Wisdom et al. (2008) examined 45 personal accounts, published in two prominent journals, and analysed them using qualitative methodology. They included first person accounts and those offered by clinicians, researchers, or family members. Meanwhile, Ridgway, (2001) identified 25 first person narrative accounts, choosing four of these to analysis their experience of recovery from schizophrenia. Participants in most studies lived in the community (Tooth, 2003; Noiseux & Ricard, 2008; Romano et al., 2010; Kalathil et al., 2011; Patterson et al., 2011; Beck et al., 2012; Wood et al., 2013) or had been admitted to a rehabilitation unit. A few studies included participants who had been admitted to a mental health hospital (Noh et al., 2008; Mezey et al., 2010; Romano et al., 2010).

Bradshaw et al. (2006; 2007) and Armour et al. (2009) explored patients' lived experiences of recovery from various perspectives. Bradshaw et al. (2006 & 2007) used a longitudinal study carried out over a period of three years; from which two articles, each reporting on a different aspect of the study, have been published. Bradshaw et al. (2006) explored recovery from severe mental illness, from the perspective of 44 participants who were at the initial phase of treatment; that is within the first six months of diagnosis. In the second publication it becomes evident that the longitudinal study was divided into three phases (Bradshaw et al., 2007). The aim of the final phase of the study was to explore the experience of recovery from severe mental illness, three years after the participants received their initial treatment. Whilst Armour et al.'s (2009) study was part of Bradshaw et al.'s (2006 & 2007) study, the focus for their paper was on the meaning of recovery from severe mental illness, as perceived by nine African Americans participants, selected from the larger sample of 44 participants.

### **2.3.8 Data Collection and Analysis**

Out of the 75 participants interviewed in the study undertaken by Hoffmann & Kupper, (2002), four participants, who are said to illustrate the varied stages taken by individuals in the recovery process, were interviewed for further development of a case study. It is interesting to note that other researchers (Spaniol & Koehler, 1994; Torgalsboen & Rund, 1998; Liberman et al., 2002) also highlighted people living with mental illness acknowledged that their recovery takes place in different stages, which are unique and individualised. Jenkins and Carpenter-Song (2005), in their ethnographic study of the experience of recovery from schizophrenia, observed 90 participants taking second generation antipsychotic medication. While a number of studies analysed data using thematic analysis (Ridgway, 2001; Spaniol et al., 2002; Tooth et al., 2003; Ng et al., 2008; Thara, 2012), the one undertaken by Jenkins and Carpenter-Song (2005) is the only one that used narrative data analysis.

Ridgway (2001) used computerised autobiographic data to explore the journey of recovery of four women (Deegan 1988; Leete, 1989; Lovejoy, 1982; Unzicker, 1989). A detailed discussion of some of the women's perceptions of recovery follows later on in this chapter. These women were identified as pioneers of a contemporaneous concept of recovery from mental illness. The researcher used data collected from a previous study that had been stored electronically. Apart from possible ethical implications, namely using the data for a purpose the participants had not consented to, the disadvantage of using secondary data is that it is likely to have been initially collected for a different purpose than what it was subsequently used for. In other words it is likely that the data might not have been suitable to answer the subsequent research question (Saunders et al., 2009). Ridgeway (2001) used a constant comparative method to analyse the narratives, initially identifying themes from each individual narrative,



then constantly comparing these across the four narratives to finally develop major themes, as such, strengthening the authenticity and validity of her findings (Saunders et al, 2009).

Ng et al., (2008) used focused groups to explore the meaning of recovery from eight people living with schizophrenia. Data analysis generated 18 categories of recover, and these were summarized into four sub headings as follows: recovery meant more than remission of symptoms; acknowledging the need to take medication as a way of preventing relapse; the lack of hope and feeling of helplessness, while assuming that those not affected by mental illness had no worries; and that others (family, friends and professionals) enhanced recovery from mental illness. In a later study, Ng et al. (2012) employed a qualitative method to investigate how people living with schizophrenia recovered from hearing voices (auditory hallucination). In-depth interviews were collected from 20 participants living with schizophrenia. Pilot interviews were conducted on two adults living with schizophrenia, to help the researches develop a four section semi structured questionnaire for conducting the interviews. Participants consented to interviews being digital recorded, and all were conducted in Chinese, and these were replayed and transcribed in Chinese by two social work students. Transcribing the interviews in Chinese is significant in that it ensured authenticity and accuracy of the findings. Not only did this ensure originality of participants' experience of hearing voices, but it also allowed the researchers to refer back to the interviews and ensure that the meaning was not altered during the processes of analysis and language interpretation (Ng et al., 2012).

Lam et al., (2011) used a qualitative study to explore the meaning of recovery from psychosis for those who experienced first episode mental illness. The interviews were audio taped and content analysis was used to identify major themes. The themes identified were; controlled symptoms, being compliant with medication, the positive outcomes of living with mental

illness, fear of side effects from the medication and being stigmatised by others. In India, Thara (2012) explored peoples' perceptions of recovery from schizophrenia. Open ended questions were employed with 100 participants, asking them to explain what they considered constituted recovery. Participants were also given a list of literature based indicators of recovery. The list was developed alongside members of the health care team, as well as getting first-hand information from a group of patients (25), carers and significant others/families. Further questions for subsequent interviews were developed during initial interviews, and were incorporated into the next interview. The following common themes were identified as being associated with recovery: remission of symptoms; returning to their social life; the ability to take responsibility of one's life; and to stop taking medication.

### **2.3.9 Findings: peoples' experiences of recovery**

The experience of mental illness is associated with an elements of loss in a number of areas; one's identity, dignity, and self-worth (Wisdom et al., 2008); and being lost in the community, because life continues and things happen where those experiencing the illness felt they were excluded (Bradshaw et al., 2006).

While the findings of the study undertaken by Torgalsboen and Rund (2010) confirmed that recovery occurs for people living with schizophrenia, it also indicated that recovery from schizophrenia is quite rare, suggesting that the likelihood is lower compared to recovering from other forms of mental illnesses. According to Torgalsboen & Rund (2010) both intrinsic and extrinsic factors, for example the individual's desire to recover, along with the input from family members and professionals, play a significant role in promoting recovery. In Torgalsboen & Rund (2010) study most patients' emphasized the importance of positive

contributions made by the therapist, namely; unconditional acceptance and caring and empathetic understanding. Participants in the study stated that it was the ‘human qualities’ within the therapist that enhanced their recovery from schizophrenia. These findings concur with other findings (Baker & Strong, 2001), in which personal and environmental factors were acknowledged as playing a significant role in enhancing the recovery of people diagnosed with schizophrenia.

Participants in Tooth et al.’s study (2003), identified 111 elements of recovery that were then grouped into six main headings; determination to get better; illness management; self-help; acceptance from friends; negative aspects of medication and health professionals. The long list of elements suggests that recovery from schizophrenia is both a complex and dynamic process that can be best defined by those who experience it. The majority of participants defined recovery in terms of taking responsibility of one’s illness and having an organised structured lifestyle (Tooth et al., 2003). Few participants defined recovery in terms of remission of symptoms. The findings from Tooth et al.’s (2003) study are in keeping with more contemporary approaches to recovery, with the main focus being on the recovery model, as opposed to the medical model, which advocates for being ‘cured’ from the mental illness as evidence of recovery.

All of the studies reviewed acknowledge that the definition of recovery is best described by people who experience mental illness, and an acceptance that such perspectives vary. In contrast to Tooth et al.’s (2003) study, participants in Jenkins and Carpenter-Song’s (2005) study linked recovery with experiencing minimal symptoms and taking medication to avoid readmission to hospital as a result of a decline in mental state. The majority of participants in

this study (Jenkins & Carpenter-Song, 2005) also believed that they are solely responsible for their recovery, being optimistic that once recovered their quality of life would greatly improve. This suggests that patients living with mental illness have hope for something better, an improved quality of life. In a Canadian study (Piat et al., 2009) involving 54 participants, two contrasting meanings of recovery were identified. The majority of the participants (41) defined recovery in terms of illness, cure, taking the right medication and returning to one's normal self. This was in contrast to the remaining (13) participants, who defined recovery in terms of the individual's internal motivation. It could be suggested that in both Jenkins and Carpenter-Song's (2005) and Piat et al.'s (2009) studies the majority of participants' defined recovery within the confines of the medical model. In several studies such restrictive views of recovery is disregarded, with definitions being expanded to account for the psycho-social context of a person's life (Smith, 2000; Ridgway, 2001; Piat et al., 2009). In each of these three studies participants defined their recovery in terms of; taking control of one's life that is, working towards personally designed goals, desires and destination; an awakening of hope for the future; living independently; and being able to secure a job with restrictions and adjustments necessitated by the mental illness.

One of Ridgway's (2001) significant findings was that recovery is a journey that is unique to each individual. This was reiterated in Tooth et al.'s (2003) study. For example, participants in both studies associated recovery with the restoration of hope; breaking through denial and achieving understanding; purposeful participation in community activities; support and partnership with others along the recovery journey; the need to have a sense of purpose in life; formulation and pursuit of achievable goals; and the need to separate mental illness from self by reclaiming a positive sense of self (Ridgway, 2001; Tooth et al., 2003). However, both

studies were undertaken with Caucasian people living in western society. In contrast, Kalathil et al. (2011) explored recovery from mental distress and resilience in African, African-Caribbean and South Asia women, living in London. The women in this study defined recovery as living a satisfactory life from their perspective, rather than from that of health professionals or significant others. While the participants in Kalathil et al.'s (2011) study were from differing ethnic groups, they were residing in a western country and therefore likely to have been exposed to western culture which could have impacted on their experiences. The key element of all these definitions of recovery is the patients' autonomy, that is, the ability to be in control in various areas of their lives, such as setting personal goals.

Within the domain of mental health, users of mental health services have different views of recovery in terms of complete remission of symptoms (traditional medical perspective) or recovering with symptoms (contemporary view). While a number of people living with schizophrenia associate recovery with minimised symptoms, for example hearing fewer voices, others believe that recovery implies that one is free of all symptoms (Ng et al., 2008). Within the literature another area of disagreement is that of taking medication. Some people who experience mental illness believed that recovery can take place without taking antipsychotic medication (Richard, 2009; Kalathil et al, 2011). In Kalathil et al's (2011) study, the participants who disagreed that medication promotes recovery, argued that the side effects lowered their self-esteem, thereby preventing them from engaging in a process of recovery promoting engagement in activities common to living in society. Other studies reveal people are convinced that taking medication promotes complete recovery from schizophrenia (Smith, 2000; Jenkins, & Carpenter, 2005; Piat, et al., 2009). In the study conducted by Ng et al. (2008), all participants defined recovery as being a complete remission of symptoms and

cessation of taking antipsychotic medication, perhaps indicating the prominence of the medical model in China. In the study undertaken by Piat et al. (2009) some of their participants believed that recovery occurs while taking antipsychotics, however, there was disparity between participants as to the markers of recovery, with 12 participants defining recovery as taking control of one's destination and level of recovery. This would require setting one's recovery goals and working towards achieving them. However, 14 participants did not believe in recovery; asserting that once diagnosed with a mental illness, one has a permanent condition; a possible indication that the stereotypical belief that people diagnosed with schizophrenia do not recover, is not only embedded in health professionals (Corrigan, P.W. & Watson, 2002), but in SUs as well.

The variations in the definitions of recovery indicate that the meaning of this phenomenon is personalised. For some individuals, their preferred definition is structured around the medical model, whilst others consider recovery within a wider psychosocial or socio-cultural context. While both of these have their place within meanings attributed to recovery, further insight may be gained by exploring the components of recovery from patient's perspectives. This may enable the establishment of common ground with regard to a definition of recovery, adding to the body of knowledge and hopefully contributing to the development of SU driven mental health services (Hoffmann & Kupper, 2002). Although users of mental health services, often those diagnosed with schizophrenia, have different definitions of recovery (Kelly & Gamble, 2005), there are general/common views to define this concept. Chadwick (2011) is of the opinion that recovery is unique to all SUs, yet she also acknowledges that there are common elements of the definition, as delineated above and below. For example, recovery from mental illness is considered by many as a transformative process that can only be defined by the person who has experienced it (Mancini, et al., 2005). Many SUs indicated that recovery is a non-

static progression where a person moves from negative situations (such as prejudice, devaluing and disempowering services, and social exclusion) to a better self (Ridgway, 2001; Chadwick, 2011; Collier, 2011; Kalathil et al., 2011). From this perspective recovery involves a transition from being overwhelmed by the illness and the associated secondary challenges; to accepting, adjusting and living a quality of life in excess of the potential limitations likely to be imposed by mental illnesses, such as schizophrenia. In her qualitative study on the experiences of four consumers (Lovejoy, 1982; Deegan, 1988; Leete, 1989; Unzicker, 1989) on their journey of recovery from schizophrenia, Ridgway (2001) identified the following themes: reinstallation of hope, insight to illness, acceptance and understanding, social inclusion, being involved and coping with changes, development of a sense of meaning and purpose, individualised dynamic journey, significance of external support in the recovery journey and changed view of one's self.

In a study carried out in a mental health rehabilitation centre in Ohio (USA) 71 patients were asked to rate ten items which they considered to be of primary importance to their recovery, the following four were identified as being highly significant to recovery (Ralph, 2000): having hope, trusting my own thoughts, appreciating and enjoying the environment, and feeling alert and alive. Ridgway et al. (2001) also described recovery from the SU perspective as being:

*“..a process, a way of life, an attitude, and a way of approaching the day's challenges....to re-establish a new and valued sense of integrity and purpose.....to live, work, and love in a community in which one makes a significant contribution.” (p. 5).*

Even though the areas of recovery may not specifically reflect the Swazi context, they provided a guide to those that could be relevant to an African context. Along with the definitions of recovery, a number of studies (Meddings & Perkins, 2002; Spaniol et al., 2002; Torgalsboen & Rund, 2002; Tooth et al., 2003; Jenkins & Carpenter-Song, 2005; Jenkins et al., 2005;

Noiseux & Ricard, 2008; Ng et al., 2008; Noh et al., 2008; Chiba et al., 2010; Lysaker et al., 2010; Romano et al., 2010; Torgalsboen & Rund, 2010; Patterson et al., 2011; Roe et al., 2011; Ng et al., 2012) describe what users of mental health services highlighted as the defining features of recovery. A summary of these features is listed below:

- Hope
- Self-determination
- Complete remission of symptoms
- Living a quality life with symptoms
- Support from others (professionals, friends, family)
- taking correct medication
- No hospital admissions
- Being accepted in the community
- Being productive
- Being in partnership with health professionals
- Acknowledging cultural diversity
- Resilience
- Relationships
- Initiative
- Insight
- Paid employment
- Being heard
- Being connected and maintaining relationships

In addition to the above, participants in Ng et al. (2008) and Thara (2012) studies associated recovery with remission of symptoms, and not taking medication. They believed that complete recovery only occurs when one stops taking medication and has a stable job. Participants highlighted that although family and friends maybe challenging during one's journey of recovery from mental illness, they also acknowledged the importance of their support in



promoting recovery. In contrast, the participants in Lam et al.'s (2011) study acknowledged that recovery occurs in the presence or absence of symptoms, and that taking prescribed medication promoted their recovery. Participants in this study also acknowledged the positive experience of living with mental illness and traveling the recovery journey. Some of their perceptions of hindrances to their recovery were side effects from the medication and the stigma attached to living with mental illness. Participants in Lami et al.'s study mentioned that society's reaction to their diagnosis prevented them from disclosing this to organizations such as universities/colleges, work places, and amongst their peers.

The findings in Ng et al., (2012) study brings into perspective the socio-cultural dynamics of recovery and living with mental illness. While some participants chose and managed to ignore the voices, others were terrified by them, and welcomed support from family and significant others, while seeking medical interventions. A number of participants tried different therapies in dealing with the voices, but the voices did not go away. Others believed that the voices were caused by evil spirits, and that worshipping the Chinese gods could help. After being attended by a medium and drinking an 'amulet tea,' one of the participants said that the voices vanished for some time, but returned, and it was then that he sought medical advice. I have observed a similar trend in Swaziland, and this has been discussed in the previous chapter. In the study undertaken by Ng et al. (2012), all participants had medical intervention, and they felt that compliance with medication was paramount in their recovery journey. Most participants in Thara's (2012) study associated recovery with remission of symptoms, and having no relapse in their mental state. Being able to resume one's previous roles and one's ability to cope with responsibilities and taking medication was also indicated as important facets of recovery.

An exploratory study on the experiences of recovery was conducted amongst 50 people living with mental illness from black and minority ethnic (BME) group of people living in Scotland. Participants acknowledged the existence of recovery, indicating that it was a unique, gradual and individualized journey, and that hope is an essential entity of the process. Participants identified peer support, inclusion and identity as enhancers of their recovery; with hindrances to recovery including stigma associated with the illness, lack of information about the illness being given to them and significant others, and unrecognized cultural values within groups promoting mental health (NHS Health Scotland, 2008).

### **2.3.10 Definition of recovery**

Leam et al., (2011) conducted a systemic review on 97 personal stories of people living with mental illness, in which thirteen characteristics of defining recovery and five processes of recovery were enumerated. In view of the findings identified above, and in undertaking this literature review I realised that a significant number of studies define recovery within the same characteristics and processes as Leam et al. (2011). As such, these have influenced my discussion of the findings on the definition of recovery from mental illness, enhancers and impediments which follows below.

One of the overarching characteristics of recovery is that of it being an active process whereby SUs must actively and willingly participate in the process, rather than being passive recipients of services. In a number of studies participants defined themselves as directors of the recovery process (Pejlert et al., 1999; Tooth et al., 2003; Piat et al., 2009; Lysaker et al., 2010; Bromley, et al., 2013; Armour et al., 2009; Marshall et al., 2009; Romano et al., 2010; Leam et al., 2011). To some experts recovering from mental illness is a process of trial and error (Tooth et al., 2003; Romano et al., 2010), but one whereby the person retains control.

A number of studies indicated that participants defined recovery as a complex, non-linear and dynamic process and ongoing journey, which can only be individually defined (idiosyncratic, peculiar, personal). It is said to be a process which leads to growth, healing and transformation of those who experience it (Young & Ensing, 1999; Smith, 2000; Ridgway, 2001; Tooth et al., 2003; Jenkins et al., 2005; Mancini et al., 2005; Bradshaw et al., 2006; Noiseux & Ricard, 2008; Pitt et al., 2007; NHS Health Scotland, 2008; Piat et al., 2009; McKay, 2010; Romano et al., 2010; Leam et al., 2011; Kalathil et al., 2011; Patterson et al., 2011; Beck et al., 2012; Wood et al., 2013). As well as the above, Young & Ensing (1999), Smith (2000), Torgalsboen & Rund (2002), Andresen et al (2003), Tooth et al (2003) Noiseux & Ricard (2008), Armour et al (2009) and Romano et al (2010) added that the journey is multidimensional and comprises of complex stages or phases.

As an idiosyncratic process, people recovering from schizophrenia gradually go through a life changing experience at their individual pace, during which time a number of changes occur. Such changes include; a renewed sense of hope after despair, redefining self, recreating a new sense of self-worth, re-kindling hope for improvement, re-building a sense of self, reestablishing identity, re-defining self, improving quality of life, learning and relearning how to live with symptoms, need to accept a new self, strong desire to change, re-integration of self and the illness, accepting the irreversible changes within one's self and life in general (Pejlert et al., 1999; Young & Ensing 1999; Ridgway, 2001; Smith, 2000; Spaniol et al., 2002; Torgalsboen & Rund 2002; Andresen et al., 2003; Knight et al., 2003; Tooth et al., 2003; Jenkins & Carpenter-Song, 2005; Bradshaw et al., 2007; NHS Health Scotland, 2008; Noh et

al., 2008; Wisdom et al., 2008; Piat et al., 2009; Romano et al., 2010; Lam et al., 2011; Leam et al., 2011).

A number of studies revealed that participants acknowledged that they considered recovery even in the presents of symptoms and while taking medication (Hoffmann & Kupper, 2002; Torgalsboen & Rund, 2002; Spaniol et al., 2002; Albert et al., 2011; Patterson et al., 2011). While others (Albert et al., 2011; Leam et al., 2011; Kalathil et al., 2011) found that recovery occurred even with little professional support, but also acknowledged support from professionals and the promotion of a therapeutic environment could aid the process of recovery.

Findings from previous studies reveal that some people living with mental illness associated recovery with being cured from the illness and returning to being normal, that is returning to a previous state of function and responsibilities before the illness, for example taking care of their families, paying bills and sustaining employment. Having no symptoms of the illness, and being able to identify causes of relapse, and dealing with them to avoid hospital admission was considered highly important in defining recovery. Recovery was also subjectively described in terms of improved physical health and having a good quality life (Meddings & Perkins, 2002; Tooth et al., 2003; Jenkins & Carpenter-Song, 2005; Borg & Davidson, 2008; Ng et al., 2008; Wisdom et a., 2008; Mezey, et al., 2010; Romano et al., 2010; Thara, 2012 Armour et al., 2009; Piat et al. 2009; Kalathil et al., 2011). Additionally, participants in the studies undertaken by Jenkins & Carpenter-Song, (2005); Ng et al., (2008); Piat et al., (2009); Thara, (2012) linked recovery with not taking antipsychotic medication as a significant indicator of recovery.

Maintaining good relationships with family, friends and significant others was also identified to indicate recovery from mental illness (Tooth et al., 2003; Ng et al., 2008; Lysaker et al.,

2010). Some studies (Meddings & Perkins, 2002; Andresen et al., 2003; Mancini et al., 2005; Pitt et al., 2007; Kalathil et al., 2011; Roe et al., 2011) suggest the definition of recovery for participants went beyond that of health practitioners. For example, psychiatrists defined recovery in terms of symptom control and medication compliance, while patients defined it in terms of quality of life (Leamy et al., 2011).

### **2.3.11 Hindrances of recovery**

Commonly perceived as hindrances to recovery were; side effects from medication, paternalism, coercive treatment, staff's attitude, stigma, lack of knowledge, emotional state, not achieving, cultural issues, racial oppression, limited resources to meet basic needs, vulnerability and the impact of physical health to their recovery ( Chernomas et al., 2000; Jenkins et al., 2005; Mancini et al, 2005 Bradshaw et al., 2006; Ng et al., 2008).

Side effects from taking medication were highlighted as one of the main causes of hindrance to recovery from mental illness. These included weight gain, drooling, tiredness/drowsiness, most of which hindered participants from taking initiatives to pursue their goals, because they felt confused at all times. Linked to this issue was the experience that some doctors were too busy to consider alternatives, or at least talk to patient's about the side effects of medication (Pejlert et al., 1999; Chernomas et al., 2000; Jenkins et al., 2005; Mancini et al, 2005 Bradshaw et al., 2006; Ng et al., 2008; Lam et al., 2011). Coercive treatment exacerbated fear and vulnerability, and this was reflected in some of the strategies to promote recovery, which participants felt were mostly professional-led and did not address their unique needs (Pejlert et al., 1999; Tooth et al., 2003; Mancini et al, 2005; Kalathil et al., 2011). Some studies revealed that recovery was hindered by over protection and control from family and professionals (paternalism). While they experienced the courage and energy to venture into unfamiliar avenues, participants talked of being overwhelmed by restrictions so that opportunities were

missed. This led to passive adjustment and acceptance that their illness was incurable, an idea in keeping with a medically dominated perspective (Pejlert et al., 1999; Ridgway, 2001; Tooth et al., 2003; Mancini et al., 2005; Bradshaw et al., 2006; Ng et al., 2012). Studies undertaken by Chernomas et al., (2000); Ridgway, (2001); Tooth et al. (2003); Mancini et al., 2005; Bradshaw et al., (2006); Ng et al., (2012) showed that recovery from mental illness was hindered by staff's indifferent and judgmental attitudes. Some professionals' use of negative language and their display of 'expert knowledge' giving them power over patients, humiliated them and exacerbated feelings of low self concept. They alluded to the fact that the health care system focused on the illness such that as people they felt invisible. In contrast, Tooth et al. (2003), Ng et al., (2008) and Mezey, et al., (2010) found that lack of knowledge about types of mental illness and prescribed medication hinders recovery by preventing cooperation and compliance from patients and others who would usually take on a supporting role. In addition to dealing with mental health problems, the literature review also indicated that people living with mental illness identified physical health to be important in their recovery journey. In a number of studies participants felt that dealing with side effects, psychotic symptoms as well as with other physical conditions has an impact in their process of recovery (Pejlert et al., 1999; Smith, 2000; Jenkins et al., 2005; Ng et al., 2008).

Reintegration into the community has been found to be hindered by stigma, which may manifest in the form of social alienation from employees (Chernomas et al., 2000), and family (NHS Health Scotland, 2008), friends and professionals (from where they were seeking help, such as doctors, police and nurses (Knight et al., 2003). Consequently, such experiences can hinder independence and promote boredom, give rise to feelings of rejection and not achieving, and a sense of having no purpose (Smith, 2000; Ridgway, 2001). Lack of employment and

subsequent financial constraints and the inability to meet daily needs (food) can be a predominant problem amongst people living with schizophrenia (Chernomas et al., 2000; Smith, 2000; Ridgway, 2001; Spaniol et al., 2002; Knight et al., 2003; Tooth et al., 2003; Jenkins & Carpenter-Song, 2005; Bradshaw et al., 2007; NHS Health Scotland, 2008; Armour et al., 2009; Mezey, et al., 2010; Lam et al., 2011; Manuel et al., 2012; Ng et al., 2012; Bromley, et al., 2013). Living in the community was found to be risky by participants in Mezey, et al.'s (2010) study, while Smith (2000) revealed that some people living with mental illness feel vulnerable when living in the community because of possible pressure to engage in high risk and unplanned behaviours.

Jenkins & Carpenter-Song (2005); Mancini et al (2005); NHS Health Scotland (2008); Ng et al (2008); Kalathil et al (2011); Lam et al (2011); Ng et al (2012) revealed that a lack of cultural diversification in mental health care, together with limited cultural understanding hindered recovery, as it often lead to persistent cultural conflicts between patients and professionals. Additionally, racial oppression has been noted to further impacted on the sense of self-worth amongst black minority and ethnic groups (Spaniol et al., 2002; Armour et al., 2009; Kalathil et al., 2011).

All the negative experiences which hinder recovery from mental illness aggravate negative intrinsic feelings (despair, denial, withdrawal, viewing one's self as having a mental disorder rather than recovering from it, low self-esteem, no hope, lack of motivation) which have been identified to further compromise the recovery process (Ridgway, 2001; Mancini et al, 2005; Bradshaw et al., 2006; Mezey, et al., 2010; Beck et al., 2012). Before discussing findings from literature on enhancers of recovery, it is worth pointing out that resilience was perceived as

both a hindrance and an enhancer of recovery in the study carried out by Kalathil et al (2011). Resilience as an enhancer of recovery encompasses an attitude of fighting through difficult times along the recovery journey, while negatively it relates to patients feeling that they were sometimes expected to be resilient even when coercively treated by professionals or those deemed to protect the vulnerable (Kalathil et al. 2011).

### **2.3.12 Enhancers of recovery**

Most studies found that staying connected in some form of relationship was paramount to recovery from mental illness. Valuable relationships were those with family members, peers, neighbours, particularly where financial, emotional and social support were readily available, and staff. Staff were valued for; sharing health information, facilitating meaningful activities, collaborative support and understanding, providing emotional support, support in dealing with voices, assistance with accomplishing personally set goals, and promoting dependence and opportunities to make informed decisions. (Pejlert et al., 1999; Smith, 2000; Ridgway, 2001; Hoffmann., & Kupper Z., 2002; Meddings & Perkins, 2002; Spaniol et al., 2002; Tooth et al., 2003; Mancini et al., 2005; Bradshaw et al., 2006; Bradshaw et al., 2007; Noiseux & Ricard, 2008; Ng et al., 2008; NHS Health Scotland, 2008; Noh et al., 2008; Wisdom et al., 2008; Marshall et al., 2009; Lysaker et al., 2010; McKay, 2010; Mezey, et al., 2010; Kalathil et al., 2011; Roe et al., 2011; Manuel et al., 2012; Ng et al., 2012; Bromley, et al; 2013; Wood et al., 2013).

The importance of hope and optimism about the future was revealed in a number of studies (Pejlert et al., 1999; Chernomas et al., 2000; Smith, 2000; Ridgway, 2001; Hoffmann & Kupper, 2002; Meddings & Perkins, 2002; Andresen et al., 2003; Tooth et al., 2003; Noiseux & Ricard, 2008; NHS Health Scotland, 2008; Noh et al., 2008; Chiba et al. 2010; Lysaker et al., 2010; Mezey, et al., 2010; Torgalsboen & Rund, 2010; Chadwick, 2011; Beck et al.,



2012; Bromley, et al; 2013; Wood et al., 2013). These studies acknowledged that having belief in the possibility of recovery motivated people to aspire to achieve more, and as a result increases the level of self-esteem and creates a positive sense of self.

Having been through the experience of mental illness, some studies reported participants felt reconstructing a positive sense of identity was important in recovery. This entailed overcoming internal and external stigma, with ways to facilitate hope and being part of a community being some of the strategies identified as facilitating the development of identity (Pejlert et al., 1999; Andresen et al., 2003; Wisdom et al., 2008; Mezey, et al., 2010; Torgalsboen & Rund, 2010; Bromley, et al., 2013). Studies carried out by Smith (2000); Ridgway (2001); Hoffmann & Kupper (2002); Andresen et al (2003); Tooth et al (2003); Wisdom et al (2008); Marshall et al (2009); McKay (2010); Romano et al (2010); Chadwick (2011); Thara (2012); and Wood et al (2013) identified that having meaning in life enhanced recovery. For example, through setting of realistic goals, assuming social roles, developing insight, introspection, understanding and acceptance, engaging and full participation in meaningful activities, and by formulating a structure or routine for daily life.

A number of studies (Chernomas et al., 2000; Ridgway, 2001; Meddings & Perkins, 2002; Andresen et al., 2003; Knight et al., 2003; Tooth et al., 2003; Jenkins & Carpenter-Song, 2005; Bradshaw et al., 2006; Borg & Davidson, 2008; Piat et al., 2009; Lysaker et al., 2010; Smith, 2000; Marshall et al., 2009; Kalathil et al., 2011; Wood et al., 2013) indicated that empowerment in different areas can enhance recovery from mental illness, including; the power to take personal responsibility, being control over one's life, focusing upon strengths, self sufficiency, confidence, striving for independence, positive self image, identification of inner

strength, resilience, being independent, and the ability to persevere. According to Chiba et al., (2010) there is a strong correlation between recovery from mental illness, high self esteem, resilience and empowerment. When empowered people living with mental illness are not only resilient about their recovery, but also have a sense of self worth which promotes their focusing on self they are more likely to succeed in maintaining their recovery.

A number of studies emphasised the contribution of spirituality in mental health recovery. The view of BME was found to be different from that of other participants, where spirituality for BME meant trust in God and for others it was a general belief in any supernatural being (multi-faith). Recovery from mental illness is said to have been enhanced by not only trust in the supernatural being, but also by the support given by members of the religious group participants identified with (Chernomas et al., 2000; Hoffmann & Kupper, 2002; Tooth et al. 2003; Noh et al., 2008; Armour et al., 2009; McKay, 2010 ; Bromley, et al., 2013). As a result of the support they received, caring for others did not only give feelings of being needed, but it also provided a way of giving back to the community or church (Jenkins & Carpenter-Song, 2005; Bromley, et al., 2013).

Consideration of various cultural practises and values when supporting people experiencing mental illness was identified as being integral to recovery. Studied indicated the importance of staff's understanding and recognition of diverse culture when delivering care, and being flexible to patients' desire for alternative therapies (Mancini et al., 2005; Ng et al., 2008; NHS Health Scotland, 2008; Armour et al., 2009; McKay, 2010; Lam et al., 2011; Manuel et al., 2012). For example the study conducted by Ng et al (2012) revealed that recovery was facilitated by patients' use of cultural practises in dealing with hearing voices. In addition, a

number of studies revealed the importance of taking medication in promoting recovery, acknowledging that this improved quality of life, and prevented hospitalisation (Smith, 2000; Tooth et al 2003; Jenkins & Carpenter-Song, 2005; Piat et al. 2009; Mezey, et al., 2010). Along with the above findings the study undertaken by Ng et al (2008) also indicated the importance of doctors prescribing the right medication and the right dose, while managing side effects in collaboration with the patients.

From the above discussion, it appears people living with mental illness/ schizophrenia have similar experiences, whether living in developing and/or developed countries. However, only four (or two?) studies were undertaken in developing countries (India and China) and it would be interesting to find out how the findings from each of these studies compare with those from African countries, such as Swaziland.

#### **2.3.1.3 Rigour**

The qualitative studies conducted by Chernomas et al. (2000); Smith (2000); Tooth (2003); Mancini et al., (2005); Noiseux & Ricard, (2007); Borg & Davidson, (2008); Piat et al (2009); McKay (2010); Romano et al., (2010); Bromley et al., (2013) promoted service user autonomy, and eliminated researchers' bias, by allowing participants to identify themselves as recovering from schizophrenia. By so doing they avoided imposing their values and beliefs regarding the recovery process on to the participants, and provided opportunity for them to freely share their lived experiences. In the study undertaken by Tooth (2003) the researcher organised two focus groups prior to starting the research, whereby SUs helped identify relevant questions for the interviews. Interviews were tape recorded and the transcripts thematically analysed. The participants received copies of the identified themes, had access to the researchers, and were kept informed of developments through a newsletter which they received twice a month. All

these activities are thought to promote authenticity and participants' ownership of the project (Saunders et al., 2009). It is suggested that by promoting full involvement of participants, researchers raise the standard of authenticity and trustworthiness of the study, while enhancing the restoration of participants' lost sense of self-worth and self-esteem (Knights et al., 2003).

The majority of the research studies on recovery from schizophrenia, as identified above, have been conducted in developed countries, with very few studies having been undertaken in developing countries such as Swaziland. In order to provide client centred mental health care there is a need for more research studies that will; a) address the needs of ethnic minority groups in developed countries, such as the one undertaken by Kalathil et al. (2011), and b) focus on mental health care in developing countries (Hugo et al. 2003; Burns, 2011). However, Pinfold (2001) emphasised how patients' testimonies play a central role in educating and facilitating an understanding of the process of recovery. Their statements about their experience of mental health problems and of their contact with a range of services appears to have the greatest and most lasting impact on the target audiences, in terms of reducing mental health stigma (Spaniol, 2001). In light of this the next section of this chapter will focus on reviewing a number of personal accounts of recovery experienced by those who have lived with severe mental illness.

## **2.4 Personal accounts of recovery from mental illness**

*"We see that recovery is an important and fundamental phenomenon.....Although the phenomenon will not fit neatly into natural scientific paradigms, those of us who have been disabled know that recovery is real because we have lived it" (Deegan, 1988, 2).*

Patients' personal accounts of their experiences of severe mental illness are of central importance when promoting recovery. To some degree this has been acknowledged by

psychiatrists, who, regardless of their adherence to the medical model, have indicated that the aspect of personal account has, for a long time, been missing in their curriculum. As a result the social context of promoting recovery has been excluded (Woesner & Kidd, 2012). In their paper on the use of personal accounts in the study of severe mental illness, Woesner and Kidd (2012) emphasised that learning from personal narratives provides mental health professionals with first hand subjective information, in patient's own words, thereby providing important insights into their lived world. The following personal accounts have been retrieved from the two journals, Schizophrenia Bulletin and Psychiatric Services, which publish SUs first-hand accounts of their experiences of living with mental illness.

Four of the personal stories discussed below are by females (Patricia Deegan, Tracy May, Gwen Davis and Esso Leete). Not only were these chosen because my study is on women and their recovery from schizophrenia, but two of them, Deegan and Leete, are amongst those who have influenced the contemporary concept of recovery from schizophrenia. The stories of these two women are also amongst the four that were included in Ridgway's (2001) study (a discussion of this paper follows later on). Although these personal accounts are out of my literature inclusion criteria, in terms of the date, because of the reasons stated above I felt that their stories would enhance my literature review. Others who have told their stories of living with mental illness include, but are not limited to, Houghton, (1982); McDermott, (1990); Unzicker, (1989); Allott, & Loganathan, (2002).

Likewise, when considering personal narratives I have also chosen to include the stories of two males, Zelt (1981) and Fisher (1996) who have both articulated their journey of recovery from

schizophrenia. David Zelt's personal account was one of the first stories to be published in the *Schizophrenia Bulletin*, and shares some of the issues raised by Deegan (1995) and Davies (2005). With regard to Daniel Fisher's (1996) story, this resonates with that of May's (2001) account her experience of recovery and as such might be useful in gaining insight as to what hinders and helps the process from a SU direct perspective. Also, and perhaps from a more personal view, I chose to include Fisher's story because of his profession as a neurochemical researcher, and I was intrigued to learn how someone who is academically successful recovers from schizophrenia to such a point as to continue with their career, and even venture into other wider opportunities, as apparent in his life story.

Following her experience of living with schizophrenia, Pat Deegan was one of the first people to advocate for change in the way individuals living with mental illness are treated. In her speech presented to faculty and field supervisors in Massachusetts, Deegan (1995) elaborated on the importance of listening to users of mental health services, and to realize that there is more to the person than the mere individual living with a mental illness. Her argument is that professionals' value of the hidden potential in people living with schizophrenia is better realized by ensuring that nursing and medical students are given the right skills during their years of training. In her presentation, Deegan went onto highlight the wisdom of professionals as those who have the ability, not only to respect people living with mental illness, but who can acknowledge and use their expertise while delivering care and support.

The goal of recovery for SUs is not necessarily to become 'normal,' but to become a different and unique being, who possess a wealth of knowledge and expertise that has come about as a

result of living with mental illness (Deegan, 1995). Deegan (1995) emphasized professionals have the ability and/or skills to motivate people living with mental illness, by bringing about hope and preventing the detrimental consequences of despair. In addition, poorly trained professionals fail to recognize the need to instill hope in SUs, but will label them as experiencing negative symptoms of the illness. As such, from Deegan's experience of isolation, despair and hopelessness, she believes that recovery from schizophrenia is enhanced by making the environment conducive to recovery by; listening to clients' needs, concerns, suggestions (having a voice) and providing SUs with as much information as possible so that they can make informed decisions. Finally, Deegan (1995) advocates that individuals who have recovered from mental illness should be employed to work with others during the early stages of recovery, believing this instills hope to those on the same journey.

Gwen Davis' life (2005) was, for a long time, controlled by Shalom, a supernatural being who influenced her to do supernatural things, and as such made her feel that she was extra special. After several hospital admissions, medication and discussions with psychiatrists, Davis states she realized that Shalom was not real. However, Davis (2005) did confess to having found comfort and company in living under Shalom's influence, describing how it was quite difficult to *"come to term with the fact that I had severe, chronic mental illness.....it had been crystal clear to me that he was just a regular, normal person"* (p.300). In addition, Davis (2005) highlights a positive aspect of living with schizophrenia, in the comfort of living with voices. While others might verbalize relief from the realization that the voices are not real, Davis indicates that for some, living with mental illness can actually be distressing when having to live without the voices. Davis (2005) stated that she was disappointed to learn that the Shalom, who had been a negative influence leading her to cut herself, was not real, and that she had

control over his influence in her life. Davis expressed ambivalent feelings towards the Shalom; disappointment due to the lack of company, and relief from the torture of a ‘supernatural being.’

As a strategy to enhance her recovery, Davis (2005) realized the importance of engaging in meaningful activities. At the same time, her autobiography reveals the struggle that individuals living with schizophrenia might face in an attempt to identify and engage in meaningful activities. She states; “*at first I was at a loss on how to go about this*” (p.300). Not only did she keep herself busy with writing, Davis believed her choice of activity enhanced her recovery, because she was able to escape the present and think about the past, validating her experiences and her feelings. According to Davis music and art reached out to her soul, making them more therapeutic than just an activity.

Additionally, the importance of friends and friendship is highlighted as one activity that took away Davis’s loneliness, especially after Shalom had been eradicated. This realization of the significance of these relationships made her feel that she was not alone. According to Davis (2005) she made the effort to invite her old friends from high school to her house, where they played games, and took walks. From Davis’s (2005) narration of her experience of living with schizophrenia, the psychiatrist also contributed to her recovery. During their regular meetings, Davis (2005) stated she felt intrinsic healing: “*talking with my doctor was very soothing*” (p.301). The psychiatrist gave her hope and empowered her, encouraging her to believe she had the ability to achieve whatever she wanted to achieve. These positive experiences uplifted Davis’s mood, such that she had a desire to accomplish greater things. In response to this, she pursued her education, completed high school, and earned an associate degree. From her



experience, Davis would like to empower others living with schizophrenia, or mental illness, and to enlighten society about schizophrenia.

While the two users of mental health services above narrated their experience of recovery from schizophrenia in the form of the first person, David Zelt (1981) used the third person when writing his autobiography for a conference presentation. Davis (2005) and Zelt (1981) wrote about a similar experience of being influenced or controlled by a supernatural or powerful authority: Shalom in Davis's story, and the Central Intelligence Agency (CIA) in Zelt's. Unlike Davis, who had a much closer attachment to Shalom, Zelt's story reflects strong feelings of fear, torture and being tormented by the CIA. Zelt believed the CIA controlled his consciousness, resulting in making his thinking chaotic. As such, Zelt stated "*the third person narrative was chosen to convey a sense of my psychological distance from the experience*" (p.527).

Despite Zelt's (1981) traumatic experience, he also talks of the positive aspect of his experience and how his 'psychological distancing technique' was very important in promoting growth. In Zelt's experience, God had a positive contribution during the time of negative experience. Even though he had such difficult moments, Zelt said that he was comforted by the knowledge that God had knowledge of all the bad things happening in the world around, and that his power supersedes that of the CIA. Zelt (1981) believed that he was assigned by God to facilitate peace and harmony on earth, like Jesus was assigned to save the world. After listening to Zelt's experience, speakers at the conference are said to have continuously given him positive reinforcement and encouragement for putting together his story. Zelt found this rewarding as he said that all the speakers repeatedly referred to his paper in a positive way, and this made him feel like he had accomplished a 'supernatural' task.

Like other users of mental health services, Zelt's experience reiterates the importance of the positive contribution others can make to the process of recovery from schizophrenia. Zelt also related how two therapists had worked together with him to smooth the process of his recovery. During his acute phase of mental illness the first therapist was confident in implementing Zelt's decision not use medication, and this yielded positive results. Even though not mentioned by Zelt as an aspect of his recovery, the therapist noted that his recovery was enhanced by; his intelligence, passion, motivation, vivacity, and warmth. These intrinsic attributes are mentioned by a number of researchers as the elements SUs bring to their journey of recovery from mental illness (Tooth et al., 2003; Noh et al., 2008; McKay, 2010).

As indicated by patients in some of the studies identified above (Ridgway, 2001; Hoffmann, 2002; Ng, et al., 2012), Zelt's second therapist highlighted the importance of working with a professional in his recovery. The second therapist was available to Zelt every day. This approach facilitated Zelt being in control of his destiny, having the liberty to contact the therapist as desired, and the therapist making time for him. In other words, Zelt was assured that he was not alone in his recovery journey. In addition, Zelt associated with people who had a similar experience, from whom he not only learnt coping strategies, but had company that kept him occupied. Lastly, Zelt's recovery was facilitated by his engagement in meaningful activities, for example, community involvement, reading and writing.

In contrast to the personal accounts above, Tracy May (2001) and Daniel Fisher (1996), offer a different experience of their recovery from schizophrenia. May (2001) was diagnosed with schizophrenia at the age of 14 years, and believed this '*robbed her of a good life*' for 21 years.

However, May (2001) also discussed some of her bad childhood experiences, namely emotional and sexual abuse. Both Fisher and May emphasized the importance of health professionals' attitude, knowledge and understanding of schizophrenia.

In her experience of recovering from schizophrenia May (2001) emphasizes the importance of language. She suggests that health professionals need to look beyond the medical jargon that they use with regard to schizophrenia and explore what lies beneath the onset of a set of symptoms. From May's perspective, for health professionals' schizophrenia has its own unique language, and as such, SUs find it difficult to communicate with health professionals. Therefore, if health professional are able to move beyond medical language and explore what triggered the illness, they would be able to more accurately address the needs of SUs. From May's experience, health professionals do not give SUs enough attention to understand their history and subsequent needs, and this leads to inadequate or wrong interventions.

Fisher (1996) is a medical doctor who undertook neuro-chemical research, in an attempt to find out the causes of schizophrenia. His research came to an end when a close relationship broke-up, and he was diagnosed with schizophrenia. After being in the ward for a while, Fisher was given leave to visit his laboratory that was close to where he was an in-patient. Even though his leave went well, and he felt extremely happy about his accomplishment, he was taken into seclusion. Fisher cried for help, asking staff to let him out, but no one was interested. This experience inspired him to become a psychiatrist, as he stated; *"I vowed that if I ever got out, I would become a psychiatrist and try to ensure that no one else would be treated in this fashion."*(p.1-2)

Both May (2001) and Fisher (1996) felt that health professionals were not interested in helping them to recover. They both tell of their experiences where the psychiatrists, during an interview, did not even give them eye contact, but focused on asking questions and writing notes. As a result they were made to feel unimportant, devalued and their need for human connection was unmet. Aristotle referred to 'Man as a social animal'; suggesting human connection is central to emotional life. For May (2001) and Fisher (1996) it was human contact they needed to enable them to deal with past hurts and disappointments: sexual abuse, in May's case; and a broken relationship, in Fisher's. But nobody listened to Fisher's account of his recovery; instead, when he scored a trip to his laboratory as 11 on a scale of 1-10 he was placed in seclusion, and ignored when he tried to offer a rationale for his response. Being listened to, is considered a facilitator in the process of recovery from schizophrenia, as it helps the individual to confront some of his/her difficult experiences that may have triggered symptoms of schizophrenia. Fisher (1996) could not speak to anybody at the hospital accident and emergency room during the early stage of his admission. He states that the staff approached him with clip boards, and their questions were like '*an attack*', demonstrating a lack of empathy. As such, Fisher said that he did not see any reason to respond. Fisher started opening up after he was approached by a gentle, calm, caring and interested member of staff, a 'corpatientsman', the lowest ranking staff, but nonetheless one who showed a genuine interest in him and valued him as a person.

Esso Leete (1989) lived with schizophrenia for 25 years. Although she describes her experience as an opportunity to grow, she also acknowledges the struggles she had through her journey of recovery, amongst which was coming to term with the illness, and making a deliberate decision to take responsibility for her life on a daily basis, by developing coping mechanisms to live

above her diagnosis. Some of the things that enhanced Leete's recovery were: changing her priorities; being more tolerant and non-judgemental of others; developing ways to use her time productively and therapeutically, she enjoyed a paying job; interacting with people who are also on the recovery journey; being in control of her thoughts and feelings and verifying suspicious feelings; enhancing concentration by writing down important information so that it would be easy to remember at a later time; and taking a low dose of medication (when required), helping reduce the intensity of symptoms.

According to Leete (1989) being stigmatised is one of the most difficult experiences and the greatest hindrance for people recovering from mental illness. Even though a person living with schizophrenia can make suggestions, or even raise concerns about his or her mental state, she or he will not be taken seriously, because of the stigma attached. However, being employed made her feel important, valued, confident and less stigmatised as she felt accepted by her community, which she suggests made her life easier.

In summary, Leete highlights the importance of dealing with stressful situations, as a way of promoting recovery from schizophrenia. She stated four strategies she has employed, and believes that they might be of use to others:

- ❖ Recognise and acknowledge that one is experiencing stress
- ❖ Point out the trigger of the stress
- ❖ Retrieve and use previous coping strategies
- ❖ Promptly implement a strategy for dealing with the stress

After reviewing the literature identified above the following questions were developed:

## **2.5 Research Questions**

- ❖ What are the experiences and perceptions of Swazi women living with schizophrenia?
- ❖ What are the perceptions and experiences of recovery from schizophrenia of Swazi women diagnosed with this mental illness?
- ❖ What promotes and/or hinders their recovery within the context of the SNPH, home and community?

## **2.6 Conclusion**

While a number of studies have been undertaken in developed countries, few studies of recovery from schizophrenia have been carried out in developing countries. The studies outlined in this chapter regarding patients living with severe mental illness, such as schizophrenia, have provided evidence that recovery is possible. The process of recovery can lead to a self-directed fulfilling life, with or without the symptoms of the illness. In developed countries there is evidence to suggest there are positive outcomes when using a contemporary recovery model in supporting SUs living with schizophrenia.

Although there is disagreement in terms of defining recovery, albeit in medical or psychosocial terms, most users of mental health services acknowledged the importance of human contact and a genuine, caring therapeutic relationship as enhancers of the recovery process. Through giving voice to patients, in terms of professional education, service design and health research, their recovery from mental illness can be enhanced through raising awareness in others.

People living with mental illness acknowledge that they have responsibility for their recovery, but at the same time appreciate ongoing support given by others. Recovery from mental illness is defined by SUs as a journey, unique to each individual. This being the case, support must be

individualized, and structured around patients' needs. The stories of people having recovered from schizophrenia can be used as evidence that people diagnosed with mental illness, including schizophrenia, do recover. Taking account of these findings will enable health professionals to gain more insight and develop a better understanding of living with schizophrenia and how the process of recovery can be promoted, as well as challenging their attitudes towards people living with mental illness, and subsequently providing better quality person centered care.

The aim of this study was to understand the meaning of recovery from schizophrenia, as perceived by Swazi women living with this type of mental illness and to explore what enhances and /or hinders their process of recovery. On completion of this PhD the body of knowledge in relation to women recovering from schizophrenia in Swaziland will add to a very limited body of knowledge in Sub-Saharan Africa and hopefully improve care for those living with this illness. A study of this kind has not been carried out in Africa and in order to find out what Swazi women, who have used mental health services, describe as important to their recovery, I have used the articles reviewed as a starting point to understand and inform my own research. This literature review has revealed that there are limited studies on women and schizophrenia (Rice, 2006), and yet specific studies are significant in the development of mental health services that would be sensitive to the unique needs of either males or females (Kohn & Hudson, 2002; Saha, 2005; Bhurgra, 2005; Hopper et al, 2007). This research is therefore based on the subjective experiences of women living with schizophrenia, in Swaziland. A theoretical approach which ensured justifies the theoretical approach chosen to conduct this study.

# **Chapter 3**

## **Methodology and Method**

### **3.1 Introduction**

The review of literature informed the methodology and the design I chose to use for this study. The majority of the previous studies reviewed in chapter 2, regarding SUs' experiences and perceptions of mental illness/schizophrenia, used a qualitative design to influence their approach. The aim of this chapter is to discuss the theoretical perspective (methodology) that guides this study, and to delineate the steps undertaken during data collection and analysis. Two paradigms used in research studies are discussed: objectivism (quantitative) and subjectivism (qualitative), with social constructionism and interpretivism being considered with regard to the latter. Central to this study is the qualitative design and in relation to this there will be further deliberation on three types of qualitative research (ethnography, grounded theory, and phenomenology), the latter considered to be the most suitable to answer my research questions. Four theorists of phenomenology, Husserl, Heidegger, Gadamer and Ricoeur, are then briefly described, as they have been influential on IPA, the phenomenological approach used in this study. IPA and its link to phenomenology is described, followed by a deliberation on the distinctive features of IPA. The method of conducting this study is then explained, and this entails: ethical considerations, participants, data collection and analysis. Finally, is a discussion on how I ensured rigour within this study.

#### **3.1.1 Research aim, questions and objects**

The aim of this study was to understand the process of recovery from the perspective of Swazi women living with schizophrenia. The following research questions were identified:

What are the experiences and perceptions of Swazi women living with schizophrenia?



What are the perceptions and experiences of recovery from schizophrenia of Swazi women diagnosed with this mental illness?

What promotes and/or hinders their recovery within the context of the SNPH, home and community?

To address the research aim and answer the research questions the following objectives have been identified:

- To gain an understanding of the meaning of recovery from schizophrenia as perceived by Swazi women living with this mental illness.
- To gain an understanding of the perceptions and experiences of recovery from schizophrenia, as portrayed by Swazi women
- To identify issues that promote and/or hinder their recovery
- To add to the limited body of knowledge regarding the experiences and needs of women living with schizophrenia in Swaziland.
- Recommend how mental health services at SNPH could effectively meet the needs of women diagnosed with schizophrenia to promote recovery.

### **3.2 Objectivism versus subjectivism**

Plato and Aristotle are the founders of quantitative research, a paradigm guided by objectivism, often referred to as positivism (Ryan, 2006). Heidegger, Husserl, Gadamar, and Ricoeur are some of the theorists' who ascribed to subjectivism, and are sometimes referred to as post-positivists (Langdrige, 2007, Smith, 2009). Positivists take an objective epistemology, believing knowledge can only be based on experimental and empirical evidence. As such, findings are replicable, meaning that the instruments used in a study by one researcher can be used by another, to yield similar findings. Usually positivist studies require a large sample size

permitting findings to be generalised to similar situations. Positivism is based on the belief that there are scientific laws and truths which can be objectively observed, studied and measured. This approach is also referred to as the scientific or empirical method, because it is considered to be free from biases, specifically those of the researcher (Gerrish & Lacey, 2010).

Even though quantitative and qualitative research approaches allow for using a systematic framework in gathering and analysing data, their differing theoretical perspectives and my research questions required me to choose qualitative over quantitative methods. Some of the principles behind quantitative research (objectively, definable and quantifiable social facts) are not applicable in answering my research questions. For example, a deep understanding of participants' perceptions, experience and meaning of a phenomenon can only be subjectively defined by those who experience it using natural techniques such as conducting interviews, rather than measuring it with instruments (Silverman, 2013).

In quantitative research the researcher must detach him/herself from the research, for example using random sampling as a way of reducing bias or avoiding contamination of the results. In addition, in quantitative research a hypotheses or theory is tested by manipulating either the environment or variables under investigation. At the end of the study the researcher will either support or disapprove the hypothesis, through the use of statistical tests, the preferred method of analysis (Treacy & Hyde, 1999; Burns, 2000; Gerish & Lacey, 2010). Findings from quantitative studies can be generalized; used to make predictions or identify trends within populations, as there is a tendency to use large samples from which data is collected, with emphasis being placed on validity, reliability and replicability of the research (Burns, 2000). Meanwhile, data collection using interviews commensurate with a qualitative design, promotes the participant's voice (Warne & McAndrew, 2004). Consequently, findings in this study may

be used to develop a theory or a model of recovery, relevant to Swazi women living with a diagnosis of schizophrenia, and possibly one that could be used or adapted for use with other women in the sub-Saharan region of Africa.

Qualitative research methods are designed to facilitate an in-depth acquisition of information, from participants' unique written or spoken words or behavioural presentation. Qualitative research has a propensity to explore a wide range of issues in relation to social phenomena and the social world human beings live in (Davison, 1994; Sandelowski, 2000; Fossey et al, 2002). It is suggested that qualitative research promotes 'humanness' because it recognizes the importance of critically learning from the person or participants who have the knowledge/experience of the topic under investigation, within the context of their social world (Burns, 2000; Polit et al., 2001). Qualitative research is designed to inquire, investigate or explore the realities or lived experience of a phenomenon, as perceived by participants involved in the study. In other words, it is the unique knowledge inherent in the participant's experience that the researcher seeks to learn.

In contrast to quantitative research, qualitative research recognised the researcher-participant relationship plays a central role in understanding human experience (Treacy & Hyde, 1999). Sample size within qualitative research is often small, with emphasis being on the depth and quality of the data, rather than quantity. In analysing the data, qualitative researchers pay particular attention to the spoken or written words, people's behaviour and the context of the research encounter, in an attempt to give meaning to the lived experience being recounted (Silverman, 2011). As such, data analysis is inductive, as opposed to being deductive, the latter

being a quantitative approach. In terms of findings, qualitative researchers may use these to formulate, either a hypothesis, or a theory (Silverman, 2011).

According to Burns (2000); *“only qualitative methods permit access to individual meaning in the context of ongoing daily life. The qualitative researcher is not concerned with objective truth, but rather with the truth as the informant perceives it”* (p.388). In addition, the multiple realities inherent in qualitative research, better captures the different interpretations people ascribe to a given phenomenon (Denzin & Lincoln, 2005). Qualitative methods allow the researcher to investigate complex issues, such as those evident in mental health, while giving the participant opportunity to have their voice heard (Holloway & Freshwater, 2007). Qualitative research can take a number of theoretical positions (Silverman, 2013).

### **3.3 Qualitative research designs**

A number of qualitative researchers have identified different research approaches. In turn, the chosen research method influences the data collection strategy and the subsequent analyses. For example, Creswell (2007) enumerated five; and Denzin and Lincoln (2005) highlighted eight approaches. In order to explicate my rationale for adhering to phenomenology as the core theoretical perspective of this study, it is worth briefly discussing a few of the qualitative research approaches that were considered. Three of Creswell’s approaches are discussed below: Grounded Theory, Ethnography and Phenomenology.

When using Grounded Theory, rather than undertaking an initial review of the literature, the researcher first collects data, and then analyses it using a system of coding (along with relevant

literature) which s/he subsequently uses to develop a theory that is based on, or grounded in, the collected data. The strength of this approach is that it is inductive, suggesting informants' experiences are not enmeshed with the researcher's assumptions and/or theoretical biases (Corbin & Strauss, 2008). Yet, this method has been criticized for its over emphasis on the idea of starting from scratch (Treacy & Hyde, 1999). By carrying out a literature review at a later stage, the grounded theory approach is likely to result in duplicating some of the studies that have already been done (Silverman, 2010). In contrast, other qualitative approaches promoting a thorough search of the literature allow researchers to confidently assert that their study is the first of its kind and/or will add to a small, but growing body of knowledge. This has been the case for my study, doing an initial literature search and reviewing available research evidence was significant, as it served to clarify that such a study had not been previously undertaken. Consequently, this study will add knowledge and understanding of African women with lived experiences of being diagnosed with schizophrenia. For some, using grounded theory enables the researcher to come from a neutral position, which means that he/she will be able to understand participants' experiences without any preconceived ideas (Simmons, 2006). However, contrary to this, it is suggested that by maintaining a neutral stance the researcher has limited input to the data collection and interpretation (Bryant & Charmaz, 2007).

An **Ethnographic approach** to qualitative research shares its theoretical stance with that of social constructionism in the sense that the researcher's focus is to study the culture, interactions, perceptions and behaviours inherent in a specific group of people (Silverman, 2013). A researcher, using ethnography, aims to observe how different members of a community, or an individual, behave and interact within their society. Reflexivity, observations and the interactions between participant and researcher, are key to this approach, giving added value as the researcher gains a vivid understanding of the participants' culture by taking

account of their interactions with the environment and the rest of their community (Reeves et al., 2008). However, the amount of time required to actually observe participants can be a drawback to using this approach, and it can also prove difficult to gain access to the community under study. As my present country of residence is the UK, coupled with the constraint of how much time I could spend in Swaziland, were factors that made the use of ethnography not suitable for this study. Moreover, the focus of this study was to gain insight into the women's experience of living with schizophrenia, and not merely to understand or observe their recovery from schizophrenia in relation to their culture.

I believe that using a phenomenological approach to this study was most appropriate, as it was most likely to empower participants by promoting positive self-value as they are offered opportunity to narrate their experiences of living with and recovering from schizophrenia. This approach is empowering to a societal group which are often subjugated through stigmatisation.

### **3.4 Phenomenology**

Within the phenomenological paradigm there are a number of philosophical positions. Four of the main philosophers (Husserl, Heidegger, Gadamer and Ricoeur) of phenomenology will be briefly discussed below, as their theories are commonly used to guide phenomenological nursing research (Wojnar & Swanson et al., 2007).

#### **3.4.1 Husserl's Descriptive Transcendental phenomenology**

The German philosopher and mathematician Edmund Husserl (1859-1938) is at the forefront of descriptive phenomenology. Husserl's phenomenology is based on Cartesian theory which views the mind as being separate from the body (Husserl, 1950, translated by Cairns, p. 16). Husserl argued that all human beings are self-driven creatures, who react to the environment based on their perceptions, rather than automatically reacting to the external environment; and

that they are conscious of their experiences, and are therefore capable of telling others about their lived experiences. He advocated that these experiences must be studied objectively, and that this was attainable when researchers listen attentively to participants, and interact with them while making careful observations throughout the process of interaction (Lopez & Willis, 2014). Husserl claimed that the qualitative researchers' goal should be to clearly comprehend participants' lived experiences, or what he referred to as their '*lifeworld*.' He believed that researchers should study phenomena as they appeared; through consciousness of the mind. Husserl's emphasis was on enumerating ways of removing all biases that would interfere with achieving a state of pure consciousness or a transcendental state (Lavery, 2003).

Husserl believed this could be achieved by 'bracketing.' Bracketing is a process of disengaging from the outside world and eliminating all bias, for the purpose of keeping the research participants' lived experiences uncontaminated, and thus promoting a clear understanding of their perception of the phenomenon. Husserl advocates that bracketing should be employed by all qualitative researchers, because failure to do so could make the researcher vulnerable to being overwhelmed by their participants' experiences, leading to confusion and failure to provide an accurate interpretation of the data (Crotty, 1996).

Husserl's concept of bracketing and maintaining a state of 'ideal subjectivity' has been heavily criticised (Sammel, 2003; Lavery, 2003; Wojnar & Swanzon, 2007) and I concur with his argument being considered with caution. The nature of this study, and the fact that I am a Swazi woman who has prior expert knowledge, and experience of working with women living with schizophrenia, compromises my ability to suspend my judgement and/or values about the topic

of this study. In light of this I felt unable to subscribe to Husserl's phenomenological approach and considered Heidegger's Interpretive Hermeneutic phenomenology as an approach to employ in my research study.

### **3.4.2 Heidegger's hermeneutics phenomenology**

Even though for me Heidegger is one of the philosophers difficult to understand, probably because of his German origin, and use of complex German words, I ascribe to some of his beliefs and values.

The word hermeneutic comes from the Greek word 'hermeneutikos' meaning to 'interpret' (Crotty, 1996; Regan, 2012). Heidegger was Husserl's student, and this is likely to have influenced his interest in studying and interpreting the living world and human experience (Lavery, 2003). While Husserl's focus was epistemological that is, to provide a foundation for knowledge, Heidegger's interest was ontological, concerning how interpretation is fundamental to human existence. He was interested in the capacity of human beings, which he referred to as 'Dasein': 'there being'; 'da' meaning 'there' and 'sein' meaning 'to be' (Crist & Tanner, 2003; Mackey, 2005). According to Heidegger, 'Dasein' is constantly interacting and influenced by the environment, or the world where s/he lives. Therefore, by understanding '*there being*' one gets insight into the world (Moran, 2000).

Heidegger believed that a human being and the world in which she/he lives cannot be separated, but the world he lives in does not determine the human being (Mackey, 2005). Similarly, Lowes



and Prowse (2001) suggest that Heidegger believed human beings are involved in a lot of activities as they interact with the world, and one of the most important aspects is their awareness of the world they live in. Heidegger's philosophy is often referred to as the phenomenology of 'everydayness', because it focuses on the impact of daily life experiences, including, but not limited to, the physical environment (Cerbone, 2006). This implies that human beings have the capacity to share life experiences, and researchers cannot understand these experiences unless their whole being is brought to account. This view encourages researchers to sensitively understand participants' experience of 'being-in-the-world' (Crist & Tanner, 2003).

Heidegger's philosophy differs from that of Husserl in terms of the principle of 'bracketing.' While Husserl advocates that qualitative researchers must abandon their experiences and values during the research process, Heidegger argues that bracketing in qualitative research is impossible, contending that when bracketing one's experiences, the researcher cannot interpret participants' lived experience.

There has been a lot of debate regarding the feasibility of achieving bracketing (Fleming et al., 2003; Lavery, 2003; Swanson et al, 2007). While Fleming et al. (2003) argues that it is not possible for a researcher to totally lay aside his previous knowledge and understanding of a phenomenon; Dahlberg (2006) advocate for a neutral stance. Instead of 'bracketing' Dahlberg advocates for the use of the term '*bridling*' implying the need to identify and acknowledge previous knowledge and experience, but being able to suspend this, to avoid stereotyping to preconceived ideas, which in turn would restrict the researcher's openness to participants'

stories and or new information. Garrish & Lacey's (2010) claim that it is important for the researcher to acknowledge previous knowledge and experience of the phenomenon under investigation, as it has the potential to enhance his/her understanding of participants' lived experiences, without contaminating their personal story. Once the researcher's knowledge has been acknowledged it can then be deliberately suspended so participants' life world remains true to their experience. This is particularly important in terms of authenticity of findings, and where data is interpreted by the researcher. Taylor (1971) described interpretation as being: *"An attempt to make clear sense of an object of study.....interpretation aims to bring to light an underlying coherence or sense."* (p.3)

The above definition suggests that interpretation involves elucidating an unknown experience. Mackey (2005) observed that numerous nurse researchers are using the interpretive approach because it is fundamental in helping them understand human experiences, rather than the descriptive approach which only aims to explain a phenomenon. It has been suggested (Benner; 1994) that the hermeneutic phenomenological approach is suitable for human experiences, where the researcher and participants collaboratively bring out meaning and understanding from collected data. The interpretive approach also requires that the researcher considers the phenomenon within the context of its natural environment. Being a Swazi woman I believe that my contemporaries are resourceful and capable of shedding light on the meaning of recovery from their mental illness. In view of Heidegger's hermeneutics phenomenology my previous knowledge and experience facilitated a more vivid interpretation and understanding of the phenomenon from the participants' perceptions. As they illuminated the meaning of recovery from their perspective, I gained a better understanding of their experiences and perceptions of living with schizophrenia. As already indicated in chapter 2, Armour et al (2009) used the

hermeneutic phenomenological method in their investigation on the African American perception of recovery from severe mental illness. The above authors confirm that hermeneutic phenomenology is appropriate to use within this type of study because *“it provides a lens to explore the role that culture plays in human interaction.....attempts to find, describe, and understand the individual’s subjective experience by systematically determining the invariant components of a particular phenomenon, for example, being a person who is African”* (p. 605).

With regard to the ontology of Heidegger’s hermeneutic phenomenology, through hearing the experiences of Swazi women and interpreting their responses I was able to better understand their social world of recovery from schizophrenia. With this in mind I believe the interpretive phenomenological approach is appropriate to guide the exploration and interpretation of participants’ subjective meaning of their experience of recovery from schizophrenia. However, as I was also a novice researcher I wanted to find a practical structure that would help me better understand and translate the lived experiences of women living with schizophrenia and in doing so I further explored Gadamer’s phenomenology, as this emphasizes the use of language as a strategy to understand peoples’ lived experience (Lavery, 2003). The use of language is significant in this study due to the need to translate from English to siSwati, and vice versa.

### **3.4.3 Gadamer’s Art of Hermeneutic**

Being a former student of Heidegger (1900-2002), Gadamer’s work was influenced by Heidegger’s phenomenological approach (Lavery, 2003). Whilst Heidegger and Gadamer agree that language is an integral part of understanding the lived experience of human beings, Gadamer terms language as ‘logos,’ a mode of communication that can help elucidate what is not verbally revealed (Regan, 2012). His main focus was on the development of a strategy on how to understand and interpret lived experiences, primarily through the understanding of

language and preconceived ideas. Gadamer believed language is unique to human beings, and has the potential to reveal meaning to others' lived experiences (Regan, 2012). In respect of being a Swazi woman conducting interviews with Swazi women, this was highly significant as I share the same language with the participants, thus having a shared acceptance of meaning and understanding as the women narrated their lived experiences.

In addition to language playing a central role in developing a shared understanding, Gadamer also acknowledged concepts such as; horizon, historical, social and culture influences as important aspects of the process (Dowling, 2005; Regan 2012). In my study, the use of two languages presented a challenge, as there was likelihood of changing meaning as I translated the text from one language to the other. Also, some English words do not exist in the siSwati language, for example the word 'schizophrenia.' This implies that a description of such words must be made; as a result, the meaning has the potential to be altered during this process. A further, more detailed discuss of translation is presented in chapter 4 of this thesis. Gadamer's philosophical view requires the researcher to understand the participants' lived experiences during the interpretation process. During this process the researcher incorporates his/her expectations and the actual meaning of the text. Gadamer argues that it is during this process the researcher gains greatest insight of the phenomenon if s/he is able to include his/her preconceptions or prejudices into the research. This requires the researcher to be consciously aware of self and in doing so will promote the capacity to see things from different angles both near and far, what Gadamer refers to as 'infusion of the horizon' (Regan, 2012).

The inability to see things from the horizon leads to over emphases on one area rather than the whole. For example, the researcher might only concentrate on issues that are nearer, those they have familiarity with, and in doing so they may miss other important aspects of the phenomena (Lavery, 2003; Regan, 2012). Regan (2012) states that the horizon enhances comprehensive interpretation by promoting understanding from what is known to more complex and unknown information. As such, even though the researcher may follow a written guide when conducting interviews, participants will lead the sessions. This suggests that further questions could be developed as the interview progresses. It is during this process that the researcher's previous knowledge and experience is incorporated, making bracketing redundant in this qualitative approach. Indeed, it has been suggested that rigour in phenomenological studies cannot be justified by the researcher's ability to stand outside the research process and bracketing within phenomenology is nothing more than an '*illusion*' (Lowes & Prowse, 2001).

Gadamer believed that interpretation takes place as people interact within a particular historical, cultural, and social environment and, as such, the interaction between participant and researcher will enhance understanding of the phenomenon under investigation. Sammel (2003) suggests that "*these histories or pre-understandings enter into any dialogical situation with us, for they serve as the foundations for our values, assumptions, and relationships*" (p. 158). Being a Swazi woman and conducting interviews amongst Swazi women, I shared some pre-understandings with participants, through a similar cultural and social environment, laying the foundation for partnership. However, while the dialogue between the participants and researcher facilitates understanding and meaning, the latter is believed never to be conclusive, as according to Gadamer, meaning is changeable, progressive and therefore open to further interpretation and reinterpretation (Sammel, 2003).

#### **3.4.4 Ricoeur's Hermeneutic of the text**

Paul Ricoeur, a French philosopher, (1913 – 2005) further expanded Gadamer's interpretive phenomenology through developing his theory of hermeneutic translation (Kearney, 2007). Ricoeur focused on understanding the theory of hermeneutic translation, emphasising the 'symbolic meaning,' through considering the text as a whole, rather than in sections, paragraphs and/or sentences. Although Gadamer and Ricoeur had a different emphasis, their philosophy is not dissimilar, particularly in relation to the '*fusion of the horizon*,' (discussed above). Both believed that a holistic approach to human experience is paramount in understanding such experience (Ricoeur, 1976).

While Husserl considered the importance of the mind in his philosophy, Ricoeur highlighted the importance of both the mind and body. In order to understand and interpret a phenomenon, he believed that the body and mind must be engaged in an endeavour to bring about an answer. Also, Ricoeur recommends that in order for human beings to understand their lives they must do this by interpreting their life as one would a narrative (Ricoeur, 2003). With regards to this study Ricoeur's work during his last years of life: the philosophy of translation, its process and challenges, is of particular significance (Kearney, 2007). Ricoeur (1976) deliberated on two main areas or paradigms of translation; the linguistic and ontological paradigms. The process of translation between human beings is influenced by their varied socio-cultural values, for example religious and cultural values. The linguistic paradigm relates to the meaning of words between one or two languages (in this study English and siSwati). Within this paradigm, translation is seen as both intra-lingual and inter-lingual, suggesting that speaking (whether to self or another person) is an act of translation, and to be considered good translation there must be transparency amongst the translators (Kearney, 2007). As such, because of the two

languages used in this study strategies to ensure transparency and maintaining originality of participants' stories were considered and a detailed account is given in chapter 4 of this thesis.

Ricoeur's philosophy is considered contemporary; he is said to be "*the most challenging, hospitable and enduring thinker of the twentieth century*" (Brennan, 2004, p. viii). Ricoeur used an eclectic approach to understanding a phenomenon, making it a much richer process than that of his predecessors (Simms, 2003). For example, based on Heidegger and Gadamer's desire to understand human experience, Ricoeur's curiosity prompted him to answer more detailed questions such as: "*How does new meaning come to be? How do we reconfigure the meanings of the past?*" (Brennan, 2004, p. ix). It is the latter that is particularly important when researching the lived experiences of those diagnosed with mental illness, as stigma is often culturally embedded and in order to address such issues reconfiguring past meanings is an essential part of the change process.

While Heidegger argues that 'being' can be reached through human existence, or Dasein; Ricoeur expands on how the meaning of 'being' comes about: that it is a continuous infinite process of interpretation that is influenced by culture, religion, politics and historical and scientific factors (Kearney, 2007). Taking such an approach to aid understanding of the phenomenon under investigation within this study has been helpful, as taking into consideration the need to address issues around language, as well as scientific, religious and cultural influences on the experiences of recovery from mental illness within the African - Swazi female context has prompted a deeper level of analysis.

In developing 'the process of interpretation of the text' Ricoeur (1981) identified the key elements of this process as: language, reflection, understanding, and interpretation; likewise,

the key concepts of his theory include: *distanciation, appropriation, explanation, and interpretation*.

**Distanciation** is defined as the ability to objectively view a text, separating oneself from the text (Ricoeur, 1981). The concept of distanciation emanates from Gadamer's fusion of the horizon (discussed earlier in this chapter). Like Gadamer, Ricoeur emphasises the reader's historical influence in understanding a text (Geanellos, 2000).

During **appropriation** the text mingles with the reader to such an extent that s/he either gains in depth understanding of the self and/or discovers new personal insight (Ricoeur, 1981). According to Ricoeur this change comes about because of the reader's openness to the text. During this process the reader's vision of the self becomes expanded as s/he has had the opportunity to incorporate other possibilities from the 'others' world, rather than being confined to the known. For example, when analysing participants' lived experiences I appropriated my understanding of recovery from schizophrenia from people living in the UK due to my experience of working with them for a number of years, but in listening to the stories I was also able to integrate my previous knowledge with that of the Swazi women. This has led to an expanded knowledge and understanding of myself and the identification of missing knowledge which can be added to the growing body of knowledge. For example, participants' experience of being in seclusion, is one area that has added information into my world view regarding patients' experience at the SNPH. I will deliberate further on this new insight in chapter 6, where I discuss my findings.



As text interpreters move back and forth within the text during the process of analysis, Ricoeur's concepts of interpretation (*distanciation, appropriation, explanation, and interpretation*) are used throughout (Tan, et al., 2009). The process of interacting with the text in a back and forth fashion has been rightfully emphasised by a number of phenomenologist: Heidegger (1962) referred to it as the 'hermeneutic circle'; Ricoeur (1981) named it the 'hermeneutic arc', and Smith (2009) described it as 'engaging with the text'. Consequently, it is argued that engaging with this process leads to a better understanding and explanation of the text or lived experience, consequently ensuring the rigor of the study (Geanellos, 2000).

*What type of study is this? Is it both descriptive and interpretive in its purpose? First, because of the nature of the research question: the explanation and description of Swazi women's meaning, experiences and perceptions of living with schizophrenia and recovering from it; and secondly because this has led to me in cooperation of the four theorists above, which in turn influenced my choice of using interpretive phenomenology analysis. Perhaps, this is in line with **the** notion that there is no clear demarcation of phenomenology being either descriptive or interpretive, but the decision is left to the researcher' creativity and innovation (Langdridge, 2008; Finlay, 2009).*

*On the whole, even though different, the philosophers discussed previously uniquely contributed to the formulation of my theoretical perspective, and as such the design of this study. Below is an illustration of the debate I had in my mind before making this formulation of my theoretical perspective. I find these four theorists to form a continuum in their development of phenomenology. Perhaps confirming that philosophers tend to critique previous philosophers then add and modify the theories based on their new perspectives (Giorgi, 2003; Wojnar & Swanon, 2007). For example, not only did Gadamer build his 'infusion of the horizon' from Husserl, but he also influenced Ricoeur's theory of interpretation (Smith, 2009). As such, I feel that, to some extent, certain aspects of their theoretical perspectives contributed to my study. Reflexivity, for example, is key in promoting trustworthiness of qualitative studies (Finlay & Gough, 2003; Langdridge, 2007). Is this linked to Husserl's ideology of 'bracketing;' only having additional strategies of how the researcher can deal with his or her subjectivity and biases? I found the use of two languages in this study to be a challenge, so that choosing between the philosophies of Heidegger and Ricoeur was <sup>opaque</sup>, I found their beliefs to complement each other. Maybe, like Lowes & Prowse (2001) highlighted, nurses, for a long time, have relied on philosophies not specific to their domain, but those which are related to their field (like psychology), it is time nurse researchers focused on those specific to their sphere of influence. Nevertheless, in the interest of limited time and word count, I made a decision to stick to the interpretive phenomenological approach, as <sup>discussed</sup> below, mainly because the IPA is suitable in digging for answers to my research question, from participants' stories, and also allowed me as a researcher, opportunity to interpret participants' stories, considering that this is a significant element when working with data for participants of a non-English speaking society.*

### **3.5 Phenomenology and Interpretive Phenomenological Analysis (IPA)**

Phenomenology aims to understand the meaning of human experiences through detailed descriptions of the phenomenon being studied, and seeks to understand how people experience and interpret their world by trying to establish, embrace and explore the complexities of that experience (Creswell, 2003). Using this approach allows the researcher to investigate the lived experiences of either an individual or group, from the perspective of those who experience it (Merriam, 2002; Denzin & Lincoln, 2005; McNamara, 2005; Creswell, 2006). To do this the researcher needs to recognize the multiple realities constructed separately by each individual, who through the process of engaging in the research, are given voice (Mason, 1996; Denzin & Lincoln, 2005).

One of the reasons for choosing a phenomenological approach is my belief that people living with schizophrenia have a lot to contribute, and that uncovering this knowledge will enable professionals to help and support them appropriately during their recovery. Additionally, as already revealed in the literature review in chapter 2 people living with mental illness have talked about how their recovery has been enhanced by being involved in their care, and participating in research studies (Ridgway, 2001; Andresen et al., 2003; Jenkins et al., 2005; Jenkins & Carpenter-Song, 2005; Wood et al., 2013).

This has been clearly evidenced in other countries, especially those in the developed world, such as the UK and USA. For example, patients in the UK generated ‘100 things’ that promote recovery from mental illness in hospital (Slade, 2009). The phenomenological approach conveys to participants a sense of being valued and seen as experts, as a result they are empowered and cherished, and this leads to an increased positive self-esteem, and will hopefully lead to an ongoing healthy mental state (Taylor, 1993).

This study evolved out of my belief that once empowered and recovered, women have the potential to reintegrate into the community to either pursue their productive roles while living with schizophrenia; or perhaps adapting their life-styles to lead fulfilling lives. Nursing and phenomenology are thought to view a person as a 'whole,' subjective being, who possess the capacity to create his or her own life experiences (Taylor, 1993; Brocki & Wearden, 2005; Mackey, 2005).

This study used IPA to interpret the data. At the heart of IPA is the desire to find out what participants' say about their lived experiences, mainly through storytelling, but also by the researcher engaging with the stories during interpretation. This process enabled me, as the researcher, to achieve a deep insight into their perceptions, meaning and experience which might not have been achieved without this unique engagement (Chapman & Smith, 2002; Smith et al., 2009).

Most qualitative researchers agree that there are a number of ways of analysing qualitative data, and that the method of analysis is allied to the study's research design (Attride-Stirling, 2001; Hsieh & Shannon, 2005; Gerrish & Lacey, 2010). Using content analysis to interpret the data in this study would have been inappropriate, as this approach often relies on numerical descriptions of data, depriving findings of revealing complex human experiences (Munhall, 1994; Brocki & Wearden, 2007; Smith & Osborn, 2008). For example, content analysis might require the researcher to innumerate how many times a word or phrase is used within the given text.

Another commonly used method in analysing qualitative data is thematic analysis. It involves identification of reoccurring words, as well as analysing and reporting patterns or themes (Braun & Clarke, 2006). Even though thematic analysis is commonly used in qualitative research, there are no guidelines on how to go about implementing it, and it is argued that most qualitative researchers identify themes when analysing data (Attride-Stirling, 2001; Boyatzis, 1998; Tuckett, 2005). In contrast to thematic analysis, IPA has clear steps on how to go about analysing data, even though these are not necessarily rigid. While interpretation of data is involved in thematic analysis, it does not necessarily yield detailed outcomes of findings, as happens with the use of other methods of analysing data, for example in IPA (Pietkiewicz & Smith, 2014). Using IPA provided me with the opportunity to engage at a deeper level with participants' shared experiences (Larkin et al., 2006). Additionally, thematic analysis lacks the idiographic attribute in identifying participants' themes, and, for me, this was a very important process in giving participants a voice.

### **3.5.1 The Distinctiveness of IPA**

Phenomenology can be classified according to its purpose: descriptive and/or interpretive (Lopez & Willis, 2004; Langdrige, 2007). The purpose of interpretive phenomenology is to go beyond describing participants' experiences, and through constant engagement with the text, dig for hidden meaning within participants' stories to find out how they experienced the phenomenon: of recovery from schizophrenia (Lopez & Wills, 2004; Smith et al., 2009). The researcher is seen to take a significant role by using his or her past knowledge and experiences as s/he brings out meaning in the stories (Geanellos, 2000; Langdrige, 2007).

In light of the above and the nature of my research questions, I chose a qualitative design that took the hermeneutic/interpretive phenomenological approach. Drawing from theorists discussed above, I chose the interpretive phenomenological approach to answer my research questions on Swazi women's perceptions, experiences and meaning of recovery from schizophrenia. In choosing interpretative phenomenology, and because of the subjective nature of my research, I decided to use IPA as this approach allowed me to use both my experiences as a Swazi woman and as a mental and general health trained nurse to gain an in-depth understanding of participants' lived experience by contextualising their narratives within the Swazi socio-cultural context. Additionally, following the literature review in chapter 2, most studies have acknowledged the idiosyncratic definition of recovery by research participants, which has been generally noted to be different from the medical perspective. This being the case, because of its hermeneutic and ideographic focus in the quest of gaining insight into others' lifeworld, I found IPA suitable for use to answer the research question of this study, thus broadening knowledge in an area which could have otherwise not been revealed should IPA have not been applied.

Heidegger initially introduced the **hermeneutic cycle** (Smith et al., 2009). The hermeneutic cycle of IPA means that the process of analysis is dynamic, non-linear and promotes critical thinking, as it facilitates different views and perspectives of participants' stories. As they make sense of one aspect of data. The researcher must consider the whole narrative as data, but in order to make sense of the whole, they must first find meaning of the part(s) that make up the story. Meanwhile, that idiographic analysis must also be viewed in relationship to narratives of other participants, facilitating different ways of thinking, which leads to an in-depth perception and understanding of participants' lifeworld (Smith et al., 2009).

The merit of using IPA in this study included: a) giving participants a non-restricted opportunity to verbalise their experiences (phenomena) from their own point of view, especially (in reference to this study) using their native language; b) the perceptions and experiences of the participants were related within the confines of their own culture and familiar environment, after which interpretation of meaning was made within that context; c) the purpose of the study was accomplished through gaining added knowledge and insight into Swazi women's experience of recovery from schizophrenia (Larkin et al., 2006). While other forms of qualitative analysis (such as discourse and thematic analysis) ascribe to the interpretive engagement of the researcher with the participants' text (also referred to as cognition) IPA emphasises deeper levels of cognition. The commonly used cognition levels are: pre-reflective reflexivity, the reflective "glance at", and attentive reflection on the pre-reflective (Smith et al., 2009). IPA is unique because of the additional fourth level: Deliberate controlled reflection, and this involves seriously meditative planning and reflection on all the other three levels of reflection, as well as an account of the cognition levels (Smith et al., 2009).

The **idiographic** devotion of IPA makes it unique from most forms of qualitative research analysis (Langdridge, 2007). Recognition of the idiographic attribute is one of the core theoretical stances of IPA, where researchers are devoted to providing a detailed analysis of individual participants' stories, and extensively engaging with the text to derive how each describe or understand the phenomena under investigation in relation to others within a specific context (Smith, 2009). In light of IPA taking account of the homogeneous traits of

participants and the idiographic commitment, the researcher is enabled to make declarations about participants' related experiences (Smith et al., 2009).

The value of using IPA in analysing participants' lived experiences is its holistic approach, the contextualising of their experience within the social, cultural, religious and linguistic aspects of their life (Biggerstaff & Thompson, 2008; Weston et al., 2011). This is significant for this study due to it being undertaken in an African socio-cultural context, where, for example, there is no siSwati word for schizophrenia, and this word would need to be defined in the Swazi cultural context, rather than in English.

According to Smith (2009) there are two ways of analysing data using the IPA format: the idiographic case-study and the theory building approach. The former was suitable to use in this study, because of my small sample size, and as such, allowed me to identify themes within each of the participants' stories and latterly across stories. The theory building IPA approach leads to the formulation of a theory from the participants' themes, often associated with a larger number of participants (Fade, 2004). Theory development was not the purpose of this study; however, this could have value should the data from this study be used in conjunction with that of other studies.

Another important element of IPA is the significance of the researcher in the analysis of participants' meaning of a phenomenon. While participants' ability to express or share their life experience is significant, the researcher's beliefs, assumptions, and ability to reflect and analyse data is equally paramount in the understanding and formulation of meaning to people's lived experience (Brocki & Wearden, 2007; Smith & Osborn, 2008). According to



Smith (2004) the participant's experience along with the researcher's previous experience provides a rich dynamic interpretation of the phenomenon.

The merit of using IPA in this study included: a) giving participants a non-restricted opportunity to verbalise their experiences (phenomena) from their own point of view, especially using their native language; b) the perceptions and experiences of the participants were related within the confines of their own culture and familiar environment, after which interpretation of meaning was made within that context; c) the purpose of the study was accomplished through gaining added knowledge and insight into Swazi women's experience of recovery from schizophrenia. Using IPA boosted my confidence as a novice researcher, as while offering a step by step guide to the analytic process, it also allowed me the freedom to fuse my horizon (experience, culture, knowledge) and this lead to a rich in-depth understanding of the participants' life world.

### **3.7 Method**

The method used to collect and analyse data in this study was guided by my theoretical perspective, and ontological positions as already discussed in the previous sections.

#### **3.5.1 Ethical Considerations**

Permission to conduct this research study was obtained from the Government of Swaziland (appendix B) and the College of Health and Social Care Post Graduate Research Ethics Panel at the University of Salford (appendix C). All those participating in the study did so on a voluntary basis. They were all given a participant information sheet (appendix D) which they were asked to read and encouraged to ask questions before they made the decision to participate or not. Those who wished to participate were asked to sign a written consent form

before participating (appendix E). Prior to commencement of the interview all participants were informed of their rights to terminate the interview at any time, without it affecting their care in any way. Confidentiality of participants has been ensured by using pseudonyms rather than their real names within this thesis and will continue in any other outputs from this research.

Due to the nature of this research, the researcher had to make provision for dealing with painful memories that could be relived before, during or after interview. To address this, prior to the interview I informed each participant that at the end of the interview the recorder would be switched off and 30 minutes would be set aside to discuss any distressing elements of the interview and this would form no part of the research. I also informed participants that if they wished for more support in the longer term they would be able to access the counselling service within the OPD of the SNPH, this being previously arranged with the hospital management.

The researcher worked with SNPH staff in the OPD to purposively select participants. The OPD was chosen because those attending were considered to be well enough to live in the community, and therefore were more likely to be mentally stable, and possess the capacity to consent to participate in the study. All written information regarding the study was translated from English to the siSwati language, so prospective participants would fully understand what the research process entailed. Posters (appendix F) which informed patients about the research were placed around the OPD; the participant information sheet, together with a letter of invitation (appendix G) were distributed to prospective participants.

Those willing to participate in the study informed staff at the OPD, at which point they were given the letter of invitation and the participant information sheet, which had the researcher's contact details, in case they wanted to ask questions directly of the researcher. When potential participants contacted me regarding the study I explained the reason for the research, how they would be involved, and that they were free to withdraw their involvement at any time during the study, and that this would not have an impact on their care.

They were also given an opportunity to think about being involved, to be interviewed on the same day of attending the OPD or to return later if they preferred. This was to allow flexibility to those with other commitments or those who needed to travel far to get back home. Those who verbalised that they were willing to take part in the study were asked to sign a consent form. Even though I intended to interview a purposive sample of ten women living with the diagnosis of schizophrenia, 15 women were interviewed. Interviews lasted between approximately one and two hours. In addition, I ended up collecting data from one Swazi gentleman living with schizophrenia, because he insisted he wanted to participate, despite my explanation about the inclusion criteria of the study. Considering the moral and ethical implications of discarding the man's interview, I have included his experience in the form of a summary of his story, and this is included in appendix H of this thesis.

The collection, storage and disposal of the data has been kept in accordance with the Data Protection Act (1998). Patients willing to participate in the study were informed that all information would be kept confidential, and that written and recorded information shared during the interview would be anonymised. To ensure that this happens, participants were informed that all names would be removed from the transcripts and pseudonyms ascribed to

each of the participants. Participants were also informed that all the data obtained during the research would be solely used for the purpose of this study and any subsequent academic outputs. In addition, participants were made aware that all data would be stored on a computer that is password protected and is only accessible to the researcher. If the participant agreed, the interviews were audio taped and they were informed that these would be destroyed once they have been transcribed and analysed.

### **3.5.2 Participants**

When undertaking qualitative research the actual number of participants is not significant, but it is the depth of information generated that is key to understanding participants' experiences (Silverman, 2000; Holloway & Freshwater, 2007; Gerrish & Lacey, 2010). However, for the purpose of gaining an in-depth understanding of their experience, and discussion with my supervisors, I aimed to recruit 10-15 participants for this study. It was agreed that due to the possible vulnerability of those women attending the OPD and the need to obtain sufficient information to make sense of the phenomenon this number might suffice.

The inclusion criteria to participate in this study involved; participants having a diagnosis of schizophrenia, being above 18 years of age, and living in the community at the time of the interview. For this reason, the sample of participants is often referred to as a purposive, convenience or a volunteer sample (Burns, 2000). Purposive sampling permits the researcher to intentionally select participants who have experienced the phenomenon under investigation (Silverman, 2011). In addition, IPA researchers are keen to undertake a purposive sampling method, as it allows them to select the appropriate group which will facilitate answering the research questions (Silverman, 2010; Pietkeiwicz & Smith, 2014).

In this study, 15 Swazi women living with schizophrenia were purposively selected at the SNPH OPD. Staff at the OPD served as gate-keepers to those who met the criteria to participant, handing them the information leaflet which they were able to read while waiting to be seen by the nurses and doctors. People attending the OPD live in the community, because they have 'recovered' making them an appropriate target group for this research. Even though purposive sampling gives the researcher the liberty to choose appropriate participants, it is crucial to carefully stipulate the criterion in order to ensure that relevant data is collected from the apposite population. The accuracy of the researcher's judgment during the selection process is paramount as this helps to deal with one of the criticism of this sampling method: bias during the purposive sampling process (Burns & Grove, 1999). While samples in other types of phenomenology do not necessarily have to have similar attributes, because of the method of data analysis, IPA researchers prefer to have a homogenous sample. This is significant because during the analysis the IPA researcher aims to identify similarities and/or differences within a specific uniquely chosen group (Smith et al., 2009).

While qualitative researchers may have a plan of how they wish to conduct their study, they need to be open to unexpected changes during the research process, and as such they need to adapt accordingly during various stages of the project, (Baker & Edwards, 2012). For example, even although I intended to interview 10 women for this study, eleven women and one gentleman were initially interviewed, and although more wanted to participate, I had to inform them that I had reached the required number of participants. However, after returning to the UK I initiated a quick data analysis of the interviews, read more on data collection and attended supervisory sessions, leading me to realise the need to collect more data as a means

of developing my interviewing skills as a researcher. For example I found it was beneficial to actually spend time at the OPD interacting with patients and helping with the day to day activities of the nurses, as this enhanced the establishment of a rapport with prospective participants. As a result, by the time they volunteered to participate in the study they were relaxed and more able to freely narrate their experiences than those who I interviewed on my initial visit. Perhaps, this could be a clear indication of the need to adapt to changing circumstances and situations associated with qualitative studies (Smith et al., 2009; Creswell, 2013) or indicative of my naivety as a researcher.

### **3.5.3 Data Collection**

There are three common sources of data collection in qualitative research: interview(s), observation or review of documents (Brown & Lloyd, 2001; Merriam, 2002). I conducted interviews, using a semi-structured schedule to guide the sessions, this being the recommended way of collecting data when using the IPA (Chapman & Smith, 2002; Brocki & Wearden, 2005; Smith et al., 2009).

Most interviews took place in one of the interview rooms at the hospital's OPD. I informed the nurses working at the OPD whenever I conducted an interview, and also reminded them about the length of the session, so that they could check on the room to ensure my safety. As the SNPH is the only psychiatric hospital in Swaziland, and people travel from all around the country to access out-patient services it was not possible to give participants the opportunity to choose the setting for the interviews. However, the OPD interview room was a place they were familiar with, thereby minimising discomfort as much as I was able to. The importance of ensuring a familiar, safe and comfortable interview room was acknowledged, as providing such a place is thought to facilitate participants being able to genuinely share their experience (Morse et al., 2002; Smith et al., 2009). Two participants were interviewed under a tree within

the outpatients' department, in fact, opposite the office where they normally attend for their monthly reviews. This was because of an emergency, the room I used was being used for patients' who needed to have immediate attention. Both participants informed me that they were comfortable to talk under the tree, especially because on both days the weather was extremely hot.

One to one interviews, each lasting between one to two hours, were used to collect data. Allowing this amount of time gave participants an opportunity to freely describe their experience without any restrictions (Streubert & Carpenter, 1999). At the end of the interview, participants were given a mug with the UK flag and E10, which is equivalent to £0.50 as a token of appreciation. I deliberately did not inform participants about the token at the beginning of the interview as I wanted to facilitate voluntary involvement, rather than engendering feelings of coercion and being bound to participate. The token of appreciation might seem very little however, considering the general socio-economic situation of people living with schizophrenia in Swaziland, this money could help them buy a loaf of bread and a packet of fruits. Their appreciation was revealed on their faces as they opened their eyes wide and smiled as they received their gift, and affirmed how grateful they were to have been involved in the study.

Although participants were given an opportunity to freely talk about their experiences, they also received prompts and reminders from the researcher, who had drafted out questions, in a form of a semi-structured interview guide (appendix I). Initially I collected demographic data using structured questions. In order to make participants feel relaxed and valued as experts within the interview session, I explained that there were no right or wrong answers; and that the focus of the interview was on their experience, so that I would be doing more listening

than talking. A semi-structured guide was used during the main part of the interview, to facilitate the participants' unrestricted telling of their stories of recovery and as a way of maintaining focus in answering the research questions (Lysaker, et al., 2003). Using a semi-structure schedule to guide the interview process also allowed flexibility to follow specific responses by participant(s). I asked questions relating to their perception, experience and meaning of living with schizophrenia and their recovery from it, focusing these around home, hospital experience and the community in which they live.

Although the interview guide was written in the English language, when interviewing I translated it into siSwati so that the participants could clearly understand the information I was seeking from them, and to ensure they were better able to respond. English being their second language, using the interview guide in English could have been a communication barrier to participants, and as such had the potential to limit their authentic responses. The interviews were conducted in the native language, siSwati, in order to allow liberal, unrestricted explanation of their lived experience.

All interviews were audio- taped with the consent of the participants. Recording the interview is important, because it is practically impossible to remember everything said by participants (Silverman, 2003). Also, recording the interviews using field notes would have interrupted, and possibly distracted me from actively listening to participants' experiences. As such, I was able to hear and comprehend participants' narration, as well jotting down brief word to catch non- verbal and verbal gestures. Using audio-tapes in qualitative studies is one way of ensuring truthfulness of the research findings, in that researchers can replay the tapes with a view of improving or adding to the scripts and ensuring accuracy (Silverman, 2010).



### **3.5.4 The Analysis**

The tape recorded interviews, my field notes and the translated scripts all played a significant role during my analysis. I had to listen to the interviews several times to make sure that the translated scripts reflected participants' stories. Within my field notes were none verbal gestures or forms of communication which could not be tape recorded. By doing this I was able to gain different insights into participants' stories as I read, and re-read participants' transcripts.

To analyses the data collected I adopted the seven steps of IPA developed by Smith et al. (2009). The seven steps are reflected in the seven sub-heading below. Due to the use of two languages in this study I used IPA alongside some aspects of Ricoeur's theory of interpretation; translation being twofold: (1) interpretation of participants' lived experience and (2) interpretation of the language used by participants.

#### ***3.5.4.1 Transcribing the interviews verbatim***

The first step of this analysis involved transcribing the interviews verbatim. It is important to ensure that the originality of the transcript is maintained at all times. This equates to transcribed scripts indicating pauses, miss-hearing, and speech dynamics (Biggerstaff & Thomson, 2008). Due to the fact that interviews were conducted in siSwati, the researcher initially translated the interviews into English. In doing this it gave opportunity for my English-speaking supervisors to read and understand the participants' original data. This step was important as it provided a system of checking my own interpretation of the data. An alternative could have been to transcribe the audio taped interviews in siSwati, before translating them to English, allowing frequent referral to the original data during the researcher's analysis and interpretation. However, in light of the process I chose, it could be argued the accuracy of participants' stories

was compromised due to the researcher's translation of audio tapes from siSwati to English prior to analysis or interpretation.

#### ***3.5.4.2 Becoming immersed in the data***

I initially re-read through the script of the first participant, line by line, to ensure an in-depth accurate understanding and subjective meaning, sometimes referred to as 'immersing' one's self in the data (Cohen et al., 2000). The main purpose of doing this was to understand the interviewee's lived experience, with a view to accurately identifying themes evident within her transcript. In order to be more familiar with the participant's lived experience I read the first script several times. During this process I had to refer back to the audio taped interview for clarity and to ensure that the originality of the story remained unpolluted by translation. Smith et al (2009) emphasised that this step is significant because it encourages the researcher to focus on the participant's story; the participant becoming the main focus. Rather than reading for the purpose of summarising the text, I had to slowly read and re-read the script. It is during this stage that I reflected on some of the non-verbal reactions and gestures observed during the interview.

#### ***3.5.4.3 Initial Noting***

During this step the researcher continues to engage with the participant's story to further understand and scrutinise the initial transcript. At this stage the primary focus is on the language and the way the participant narrated her lived experience (Smith, 2009; Silverman, 2010). In the left hand margin of the first transcript I wrote a summary or phrases of my understanding of the participant's narration. Smith et al (2009) emphasised that the aim of writing notes within the text is to gain a comprehensive and detailed understanding of the lived experience. Not only did I note the participant's concerns, but I also attempted to understand why these might have become concerns. In summary, during this step I focused on describing the content of the

transcript, then explored the use of language within the given context, and highlighted significant themes emerging from the first participant's script.

#### ***3.5.4.4 Further Development of themes***

Development of themes for the first participant involves a thorough reading of the interview script with the aim of identifying themes. Themes are usually written in the form of phases or short statements that describe the main concepts of the participant's story. Themes from the first participant serve as a measure to compare and contrast with the interviews of subsequent participants (Biggerstaff & Thomson, 2008). I have included Pholile's analysis to demonstrate how an analysis of each script was carried out. Appendix J is Pholile's story with numbers inserted throughout the script to help identify the source of her quotes. The process of assigning themes to the original data is achieved by critically reading participants' data and then identifying labels or themes. Labelling themes involves abstract reasoning via the allocation of abstract terms (Smith et al., 2009; Creswell, 2010). During this step I engaged in a detailed allocation of themes on the first participant's script. Appendix K shows the steps of initial noting and further development of themes. Within the transcripts I highlighted sections that described participants' definition of recovery and things women believed either enhanced or hindered their recovery from 'sifo sengcondvo' – 'illness of the brain.' Once transcripts had been translated into English my supervisors also looked at the transcripts and identified what they considered important themes. During my supervision sessions we discussed what each had identified as a way of checking that I had not missed any important information and there was shared interpretation of some phenomena.

#### ***3.5.4.5 Identifying connections across themes***

Connecting themes encompasses re-reading the interview transcript to find out how themes are related to each other. The identified themes are the factors which constitute the main

components of phenomena being analysed. Within IPA this process entails constant reading and re-reading of the data so as to improve the researcher's familiarization and understanding of the issues that appear to be foregrounded, whilst capturing links across a group of themes. It also entailed reviewing themes; defining, naming and re-naming the identified themes and collating them in data sets in order to capture the intricacies of meaning within the various aspects of the phenomena being explored.

During this step I explored the identified themes in details, with a view of speculating, understanding and evaluating their importance (appendix L). As a result, some themes that were not related were discarded, mainly those that were not answering the research questions. Abstraction is one of the main processes I used at this stage. This involved grouping similar themes together then merging them to identify common themes. I used polarization to identify opposite themes. Contextualisation helped me to identify themes and broaden my interpretation to identify other factors (such as cultural values and beliefs) within which the theme(s) emanated. Another strategy I used in finding connections across emergent themes of the initial script was by keeping a record of the frequency of appearance of a particular theme. Smith et al (2009) emphasises that this technique should not be considered in isolation of the others, and those that appear less do not necessarily have less significance than others.

In order to ensure that my interpretation and past experience did not occlude participants' experience, throughout the data analysis I constantly referred to the original data, making sure that emerging ideas and interpretations reflected the participant's original meaning of recovery from schizophrenia (Smith et al., 2009; Weston, 2011). Additionally, instead of analysing one script immediately after the other, I did different activities as a way of bracketing previously

identified themes. This I used as a way to ensure that the identification of participants' themes was not informed by each other. I then enumerated the themes of the first script, as shown in appendix M. This process is what makes IPA an 'interpretive' method of analysing data (Munhall, 1994; Silverman, 2010).

#### ***3.5.4.6 Analysing the rest of the interviews***

The process employed on the first script above was repeated with the rest of the interview transcripts, each scripted being analysed as a unique entity. The themes which were developed during the analysis of the first interview were later used during the rest of the analysis. Also, newly emerging themes were identified and added to the analysis. Smith (2009) states that it is important to bracket the ideas or themes identified during the initial stage of analysis, allowing the analysis of each subsequent interview to focus on its content without being polluted by the findings of the first story. The focus on the 'particular,' is what makes the IPA unique from other qualitative methods of analysing data. The aim is to understand a 'particular' phenomenon, using 'particular' detailed analysis (Smith et al., 2009). As such, it became imperative for me to analyse each of the interviews individually and separately; and to bracket the ideas or themes identified during the initial stage of analysis; allowing the analysis of each subsequent interview to focus on its content, without being polluted by the findings of the first analysis (Smith et al., 2009). After analysing all interviews individually, I then identified patterns across all fifteen individual participants' themes. However, just like 'bracketing' in a Husserlian sense, this is difficult to achieve.

#### ***3.5.4.7 Identifying patterns across all scripts***

During this phase I also carefully identified similarities and differences in terms of specific elements within each individual interview across all the analysed transcripts. This step entailed a deeper level of interpretation and identification of connections and differences across themes,

and themes which are more persuasive than others. At this stage super-ordinate and or sub-ordinate themes were either merged or discharged, depending on their relevancy to answering the research question (Smith et al, 2009). A deeper level of interpretation and the enumeration of sub-ordinate and super-ordinate themes across all participants involved a number of steps. A summary of these are demonstrated in appendices N, O, and P. This resulted in relabeling some themes. The final stage when using IPA is that of presenting the findings. The findings will be presented in chapter 5.

### **3.6 Rigour**

I have used 'rigour' as an umbrella term to refer to how I ensured the quality, trustworthiness, authenticity, and or truthfulness of my study. According to Polit & Hungler (1999), because of the differences in the theoretical foundations of qualitative and quantitative designs, the terms used to measure the quality of these designs are different; with qualitative research commonly referring to authenticity/trustworthiness. While the motives and good intentions of conducting a research project are important, the significance of doing a qualitative research study is valued by the researcher's clear demonstration of the steps and procedures employed to evidence its trustworthiness (Guba, 1981; Yardley, 2000; Silverman, 2013). In other words, a good qualitative research report must accurately reflect and/or represent the authentic description of the participants' experience (Streubert & Carpenter, 1999; Silverman 2000).

As I have already indicated in previous chapters, because of my epistemology and ontological position, the terms I use in justifying my study are those in keeping with the language of qualitative research. The following paragraphs illustrate how I ensured the authenticity or trustworthiness of this study.

To illustrate rigour within my study I chose Yardley's (2000) criteria, as her discussion is specific to using IPA. However, I have integrated some of the terminology described by the other authors, namely Guba (1981) and Polit and Hungler (1999) in my discussion. The following are strategies I used to ensure rigour in this study;

➤ **Sensitivity to context** and credibility of my study. Consent to conduct this study was solicited from the University of Salford and the government of Swaziland. Data was collected within an environment familiar to the participants, and it was easy to establish a rapport with most of them, especially with the last four participants. Choosing to conduct this study within my socio-cultural background was significant in identifying a theoretical perspective which would be suitable for Swazi women. My choice of the hermeneutic phenomenological theoretical perspective to guide this study led to the using of IPA to uncover meaning from the participant's perspective. This indicated my value of the women's expertise in their *lifeworld*, while giving me the opportunity of interpreting their stories within the context of their cultural environment. Participants were informed about their right to terminate their involvement in the research whenever they felt like it, in order to ensure that their stories were authentic and that they did not feel pressurized to be involved in the study. Because of my fluency in the English and siSwati languages, along with having a similar background to with those involved, during the analysis I managed to obtain a deep insight into their perceptions and experiences, which would have possibly been concealed should I have used a translator. A token of appreciation was given to each informant at the end of the interview to demonstrate that I valued their time to take part in the study.

➤ **Commitment and rigour.** Even though I could have conducted telephone interviews from England, I chose to conduct one to one interviews with participants, so that I could ensure a good quality of interview by attentively capturing all forms of

communication, and this in turn provided a better understanding and contextualisation of participants' experiences. During data collection I modified my interview skills to facilitate the establishment of a good rapport with participants, and this led to them freely sharing their stories. I collected data from a purposive homogenous sample based on my research questions and used a semi-structured guide and open-ended questions to encourage participants to unreservedly articulate their stories. A homogenous sample is important in the transferability of the findings (Guba, 1981; Polit & Hungler, 1999). Even though I have read about the rigorous idiographic detailed process of IPA, practically applying it made me realise its demand and need to really engage with participants' stories so that my findings were not only descriptive, but interpretive. This is evidenced by the relevant extracts from a number of participants' stories, offered in support of each of the sub-ordinate themes and the four super-ordinate themes, as outlined in chapter 5. Even though there is scarcity of African based research studies within the sphere of my study, I initially conducted a rigorous literature review (chapter 2), the body of knowledge identified acting as a backdrop in comparing those findings with the ones emerging from this study. This discussion is detailed in chapter 6 of this thesis.

➤ **Transparency and coherence.** I have included extracts from my reflective diary in this thesis, some of which reveal the distinction between my subjectivity and participants' narratives. The steps employed during the analysis have been discussed earlier on in this chapter, and an example of the analysis of one of the transcripts is included in the appendices (J, K, L, and M). Tables and graphs have been included to foster clarity of certain aspects within this thesis. Attending supervision and presenting my study to other academics (conferences and seminars) was very significant in promoting transparency and coherence, as I received feedback which made me think



critically about certain issues, which might not have been realised otherwise. This also gave me an opportunity to either adjust or elaborate on the various stages of my study (Ralph et al., 2002; May, 2004; Allott et al., 2003). I have included in chapter 4 below, a discussion of how I dealt with issues of translation and transliteration, to evidence my transparency within this study.

➤ **Impact and importance.** This study is unique and has revealed a lot of information which will influence other research studies, clinical practise, education and policy design. Perhaps including chapter 4 in this thesis will also encourage other researchers who might have been challenged by how to deal with the apprehensions of conducting studies in more than one language, to use some of the strategies I employed in ensuring the originality of participants' narratives when translating their stories from the native language into English.

### **3.7 Conclusion**

This chapter has explained and justified how I chose a qualitative phenomenological theoretical perspective and an interpretive design to gain knowledge and understanding of the experiences and perceptions of Swazi women living with schizophrenia, and how they defined their recovery from this illness. The purpose of my study is beyond Husserl's descriptive epistemological approach. My passion for this study and my previous expert knowledge (both professional and personal knowledge) made it impractical for me to detach myself from my study, so that engaging Husserl's philosophy encompassing bracketing was unattainable in this instance.

With regards to this study, Swazi women living with schizophrenia are experts in their own right and therefore best placed to educate others about their experiences of living with a mental illness and what hinders or promotes their recovery (Warne & McAndrew, 2004). Ensuring that participants' experiences are kept subjective and original is the core attribute of qualitative research (Silverman, 2010).

Gaining a deep understanding of participants' lived experiences and perceptions was the focus of this research. This process involved *interpreting* the knowledge gained in order to understand women's experience of the recovery process (Heidegger's *ontological* approach; Ricoeur's *conflict of interpretation*); and this was undertaken by developing a partnership between researcher and participant, through the use of past and present experiences of a shared culture (Gadamer's *infusion of the horizon*). While Ricoeur detailed the process of interpretation and its influence on the data and the interpreter, within this chapter I have also discussed the method I used to analyse and interpret participants' data using the IPA approach recommended by Smith et al (2009).

The quality of this study has been upheld by using rigours strategies. Keeping a reflective diary, presenting at conferences and attending regular supervision sessions was useful in that all these activities allowed a critical scrutiny into important issues, such as subjectivity, giving me an opportunity to either adjust or elaborate on the various stages of my study and thus ensuring the quality of my research. While qualitative studies tend to focus on a small sample of people their strength lies in their ability to present in-depth analysis leading to a better understanding of the phenomenon under investigation. For this reason, qualitative research studies have an important role to play in helping to develop and grow a body of knowledge pertaining to the

nuances of being human. In this study the findings serve as an example of the experience and perceptions of recovery for Swazi women living with schizophrenia or more correctly, in siSwati 'illness of the brain'. The findings of this research will add to previous and further findings of other studies exploring the African socio-cultural context of living with and recovering from such illness.

# **Chapter 4**

## **Translation and Transliteration**

### **4.1 Introduction**

*“Factors which affect the quality of translation in social research include: the linguistic competence of the translator/s, the translator’s knowledge of the culture of the people under study, the autobiography of those involved in the translation, and the circumstances in which the translation takes place. There is a need for social researchers who have to translate data from one language to another to be explicit in describing their choices and decisions, translation procedures and the resources used.” (Birbili, 2000, p.1).*

In this chapter issues around translation and transliteration are discussed. The reason for including this chapter within my thesis are briefly delineated, key terms are then defined, followed by an enumeration of the issues around language and translation I faced when conducting this study, specifically during data collection and analysis. Strategies employed in dealing with these challenges are discussed.

### **4.2 Rationale for including this chapter**

Before deliberation on my research findings, I felt that it was necessary for the reader to have insight into the processes of translation and transliteration used within this project. Interviews were conducted in siSwati and then translated to English. Some medical words that are used in western medicine, such as Schizophrenia, are not part of the siSwati language, and therefore had to be transliterated in order to give meaning and make sense of the participants’ stories. In ensuring validity, and that participants’ siSwati meaning of their lived experiences is not changed during translation, it became paramount for me to identify some theories of translation and how these were used in this study.

### **4.3 Translation and Transliteration**

Allen (1990) defined translation as a process of changing either spoken or written words from one language to another. For example, in this study the researcher translated participants’

spoken interviews from siSwati to English. In this study translation was used along with transliteration. Unlike translation, in transliteration corresponding words or letters of another language are substituted for the original (Allen, 1990). With regard to this study, translation and transliteration are important, as the interviews were conducted in the native language of the participants and then translated into English, a process that has the potential to alter meaning and consequently hinder the trustworthiness of the findings (Chen & Boore, 2009; Regmi et al., 2010). In addition, the interpretation of my English supervisors, who also looked at the transcripts, could impact further on the data, thus increasing the probability of altering participants' original meaning of experience. It is suggested (van Nes, et al., 2010) that the involvement of other translators who do not have an understanding of the original language is likely to lead to multiple interpretations due to language differences.

A positive aspect of conducting the interviews in the native language is that the participants were at liberty to share their lived experiences without language barriers, or restrictions (Twinn, 1997). Translation and transliteration have been described as inevitable aspects of qualitative research, due to the fact that the researcher collects data through interviews or observations, and these must be translated and transliterated (Regmi et al., 2010). This is a 'multilayered' process, whereby decision making is influenced by the socio-cultural context, evident throughout the translation layers (Regmi et al., 2010). Similarly, Chen and Boore (2009) suggest that the researcher is responsible for making sure that the participants' experience is not polluted when multifaceted activity becomes part of the processing of information. One of the challenges of this study was finding English words that have a similar meaning to siSwati. For example, I had to find a siSwati word for 'schizophrenia.' As such, I had to either use the same word in English or explain the symptoms of schizophrenia to the participants. As a result

of my inconsistency when using the word schizophrenia, during the first couple of interviews, I was concerned that it might have compromised the authenticity and trustworthiness of the research findings (Twinn, 1997).

Ensuring trustworthiness in qualitative research is a challenge, critical observation of the translator, back-translation and the consideration of culture and language are some of the fundamental issues that need addressing in the research process (Chen & Boore, 2009). The researcher/translator's ability to understand participants' cultural values is paramount in solving most of the translation dilemmas. The process of trying to understand the lived experiences requires the researcher to continuously make decisions and interpretations of the cultural meaning inherent in the interviews, beyond translating the language (Hsin-Chun Tsai et al., 2004; Temple & Young, 2004; Chen & Boore, 2009). As such, it becomes significant for the interpreter to have a similar cultural understanding as the research participants. In this study I translated the interviews as I shared a cultural history with the participants.

Even though as the researcher I felt overwhelmed with the responsibility of translating the siSwati interviews to English, this served as a strength to the study in the sense that I am bilingual; fluent in both English and siSwati; I share a culture and gender with the participants; and as a qualified mental health nurse I have clinical understanding of the related concepts, namely mental illness. Chen & Boore (2009) suggest that if the translator does not have any two of the above attributes, then two more translators must be involved in the process in order to ensure rigor of the research.

Tsai et al (2004) proposed that participants should be involved in translation, so they can validate their narration by confirming it has not been altered during the translation process. It is likely that the majority of those involved in this study could not translate their story into English. I am making this assumption based on the fact that most participants stated that they either did not complete their high school education (GCSE), or they wanted to go back to school to complete their GCSE. Only one participant had attained a university degree, some had not been to school, and others only completed their primary education.

Further, Tsai et al (2004) argue that even a bilingual interpreter who shares a similar culture and language as the research participant, can still bring about a wide variation in the interpretation for a variety of reasons, including; socio-economic issues, history, and immigration. As I have been living in the UK and working in mental health services in the UK for over ten years, I had to be careful when dealing with this issue during the interpretation process; mainly through ongoing reflection.

Back-translating is one of the primary strategies for ensuring authenticity when translating data (Chen & Boore, 2009). This process involves translating the translated data word for word back to the original language. This is undertaken by a number of bilingual individuals, who should not only be knowledgeable about the participants' culture, but must also have knowledge on the subject under investigation. However, Cha et al. (2007) argues that relying on back-translation as a way of ensuring truthfulness is unreasonable, as word for word translation changes the meaning of a text. For example, in order to maintain the same meaning in siSwati as in English, the order or arrangement of words might need to be changed in the siSwati

language. Therefore, the meaning of the original text is likely to be changed during the back-translating process. The use of back-translating in this study was impracticable, given that I had no access to other bilingual people with whom we could do back-translation, especially being in the UK, and having no access to funding to do this.

While conducting this study in siSwati, then translating it to English may have been problematic, the involvement of my supervisors served as a way of upholding authenticity of the findings. Because of their expertise in qualitative research and in the given topic, they checked the transcribed transcripts, producing their own analysis which we then discussed focusing on where the three sets of analysis were similar and where they differed. This process ensured the analytic process was rigorous and systematic (Smith, 2010) and was further complimented by my own reflexivity.

Ricoeur (2003) highlighted the importance of the researcher's use of language and culture, in an attempt to understand participants' lived experiences, and as such language plays a central role in qualitative studies as it serves as the mode through which participants tell their stories (Squires, 2008). The more fluent participants are in the language of expression, the more likely they are to fully explain their story to the researcher (Larkin et al, 2007; Van Nes et al., 2010). This is one of the reasons for collecting the data in siSwati, rather than English.

In regards to studies conducted in more than one language, a significant number of authors (Lee et al., 2008; Squires, 2008; Van Nes et al., 2010; Phillip, 2011) emphasise the need for clear discussion regarding the reasons behind the need for translation, along with procedures



researchers need to follow in order to maintain authenticity of findings. For example, a study may be conducted where an English speaking researcher collects data from participants who speak a different, native language. In this instance the researcher would need to use a translator to be able to understand participant's narrations, risking further compromise of the original data. In a second example, the researcher and participants might be knowledgeable and eloquent in both English and a second language, such that they could be using both languages throughout the study. However, to ensure clarity and uniformity in understanding they would need to translate the findings into one language to ensure accuracy of the data. Lastly, is a situation where the researcher collects data using his or her native language, but due to the need to communicate the study and its findings to a wider audience, translation to English becomes inevitable (Birbile, 2009). In this study, although I am Swazi and fluent in the English language, participants were only fluent in the native language (siSwati), hence the need to discuss translation issues and how they influenced the research findings.

The growing interest in doing qualitative research using other languages is significant in facilitating the increase of knowledge in different cultural contexts and societies (Regmi, 2010). In order to make the studies available and accessible to a wider population, it must be translated to the English language so that, for example, they could be published in international journals. This means that the process and impact of interpretation and transliteration must be clearly discussed within such studies (Larkin et al., 2007).

Even though qualitative researchers' interest in conducting studies in languages other than English is increasing, they are often criticised for paying little or no attention to the consequences of translation, a process that has the potential to influence the data collection and

subsequently the outcomes of the study (Temple & Young, 2004). It has been suggested that some researchers do not discuss translation issues within their studies, because of the belief that the translator has remained objective throughout the process (Temple & Young, 2004). Such an omission to detail could lead to the processes of translation and transliteration being challenged as the findings could be compromised. The discussion presented below focuses on the implications of using the siSwati and English languages, how the challenges of this were dealt with and how, in light of this, the rigor of future studies could be enhanced.

#### **4.3.1 Is it the ‘b’ that flies or ‘b’ to sleep or ‘b’ news**

Having arrived in England when he was a year old, my youngest child, Treasure, is more fluent in expressing himself using the English language than he is in siSwati, the family native language. During his visit to Swaziland five years later, he became physically unwell. One of the comments he made was “I feel sick grandma, I feel sick.” My mother then asked my son “where is the pain, show me where the pain is.....?” Meanwhile, Treasure vomited on the carpet, and felt very embarrassed in doing so. It is interesting to note that the translation and transliteration of Treasure’s statement to the siSwati language has a different meaning than it does in the English context. Treasure’s comment in siSwati is: “ngiyagula gogo, ngiyagula,” meaning “I am not feeling well grandma, I am not feeling well.” Grandma’s response or action was based on her translation and transliteration of Treasure’s comment. Yet, Treasure meant “I want to vomit grandma, I want to vomit.” Even though grandma has clear understanding of the English language, her interpretation of Treasure’s comment of “feeling sick” was different from what the child implied. Treasure associated “feeling sick” with vomiting, while grandma associated it with pain.

Similar words or statements can have different meanings in different societies. During most of the ebullient moments and conversations with my friend from Zimbabwe, she would say “*ah!*

*Futseki*.” I ignored this for some time, until she said it during a conversation with my children. It was then that I learnt that the meaning of this statement was different in Zimbabwe to what it is in Swaziland. My friend informed me that saying “Futseki” in her country literally transliterates to “ah! Go away.” While it is transliterated in a similar fashion in the siSwazi language, it is usually used when communicating with animals, such as dogs, and is considered an insulting expletive. Therefore, when communicating with human beings this word is never used kindly in Swaziland.

#### **4.4 Definition of terms**

The meaning of *translation* within this study is used to refer to the process of changing written or spoken word(s) from one language to another (Jones & Boyle, 2011). In other words, translation involves the allocation of words or ideas to either spoken or written words using another language, with the aim of maintaining the meaning of the original text or achieving maximum equivalence of meaning (Jones & Boyle, 2011). Yinha (2011) made an additional dimension to the definition of translation, stating that it is not just an exchange of different written or spoken words, but a process of communication between two or more languages, whereby there is interaction across languages, cultures and social communication.

*Equivalence* in this study refers to the process of making translated data as close as possible to participants’ narrated experiences (Miao, 2006; Regmi, 2010; Panou, 2013). Equivalence can also be used as a way of ensuring validity of findings in qualitative studies (Chang et al., 1999). This process is also seen as central to translation, the objective of which is to ensure that the originality of participants’ views is adhered to throughout the study (Miao, 2006; Yinha, 2011; Panou, 2013). However, the majority of translators use this term out of habit, rather than because there is need to do so (Farrokh, 2011). Equivalence can be divided into two types:

formal and dynamic, enhancing purposeful use of the term (Farrokh, 2011). The purpose of formal equivalence is to focus on the content and form of the document. Dynamic equivalence is based on the principle of *equivalent effect*: the ability to ensure that the translated document is as close as possible to the original text (Miao, 2006; Panou, 2013). Following the dynamics of effective equivalence, variations have been made to the description of this concept (Baker, 1992). Equivalence can be categorized into; equivalence of words, phrases, text or grammar (Baker, 1992). For example, the word 'life' can have different interpretations, even though it is an English word. In one context it could be interpreted as the 'soul,' while in another it could be interpreted as 'being alive'. All in all, the equivalence effect in translation is only a desire, and not the purpose of translation (Panou, 2013). This implies that during any process of translation, alteration or shifting from the original text is inevitable.

*Shifting* refers to changes in meaning that come about or those that may occur during the translation process (Farrokh, 2011; Panou, 2013). According to Farrokh (2011), shifts were originally defined by Catford as “departures from formal correspondence in the process of going from the source language to the target language” (p.75). While this process is inevitable during translation, if not well addressed, shifts can occur, completely altering the meaning of the original information, and as such may have an adverse outcome on the authenticity of the study. This means that there could be a major discrepancy between the translated document and the original (Miao, 2006).

However, Brislin (1970) devised a strategy to enhance equivalence during translation. Although it was not feasible to implement most of these steps in my study, perhaps clearly enumerating them below will benefit other researchers conducting research in more than one language. A detailed discussion on recommendation of dealing with translation follows in

chapter 7 of this thesis. Brislin's strategies of promoting authenticity in multiple language research:

1. A bilingual translator translates the schedule or tool for collecting data, from the original language (English) to the native/target language (siSwati), known as forward translation.
2. The recorded interviews are transcribed verbatim, before being translated into the target language (English).
3. A bilingual translator reads the transcribed script, and re-reads to familiarise him or herself with the original script, making notes where necessary. S/he then translates the data into the target language (English), in this instance from siSwati to English. This is also referred to as forward translation.
4. Without any prior knowledge, a second translator undertakes backward translation; whereby the translated text (English) is translated back into the original language (siSwati).
5. Both translators sit down to compare original text and the translated version. Variations in meaning of words are noted, such as: cultural differences and non existence of equivalent words in both languages (target and original).
6. Translators reach a consensus in terms of the best possible translation.
7. Translators spend some time reading and re-reading both the original text and translated document, comparing the translated text with the original, in order to ensure maximum equivalence. This leads to the production of a final translated document.
8. Without maintaining contact or communication, two analysts would analyse both the script written in the target language and the other in the original one.

For some, reaching a state of equivalence in translation in qualitative studies is impossible and considered a challenge to attain, even within the same language (Miao, 2006; Panou, 2013). A state of equivalence effect is impossible to attain, even between analogous languages, because the reader's translation of a script is more subjective than objective (Miao, 2006). Within this study the incorporation of Brislin's strategy to enhance equivalence within the process of translation was hindered by a number of factors, amongst which was the lack of a qualified siSwati bilingual translator. As a result I did the forward translation, but omitted the backward translation step. The majority of participants were not eloquent English speakers, making it impossible to involve them in back translation.

#### **4.5 Dealing with challenges of translation**

In qualitative studies undertaken in two or more languages, researchers must be able to anticipate and allocate specific time for translation and transliteration, regardless of the amount of data collected (Temple & Young, 2004). Regmi et al (2010) recommended that the best strategy to ensure equivalence in such studies is by engaging as many researchers as possible so that they can compare and confirm each other's findings during data analysis. He suggests that researchers could be given different task during the process of analysis, and then swap roles at a later time, as a way of checking that participants' experiences are not altered during the translation and transliteration process.

Another challenge of translation is the non-existence of some of the exact words, phrases or sentence used in the other language (Biribil, 2000). Schizophrenia, for example, is a medical diagnosis for a specific mental illness that encompass particular signs and symptoms that are experienced by an individual. While doctors at the SNPH record the diagnosis in case notes for their personal/professional use, the word schizophrenia cannot be translated into the siSwati language. In fact, the name ascribed to different categories of mental illness, as stipulated in

the ICD-10 (2010), or DSM 5 (2013) are non-existent in common siSwati language. Instead, mental illness is given one name/phrase(s), with their transliterated words in brackets; “*kuhlanya* (being mad), *kugula encondvweni* (being sick in the brain), *sifo sengcondvo* (illness of the brain).” The problem of using the word “kuhlanya” meaning “madness” is that in the siSwati socio-cultural context, it is a sign of disrespect and/or suggests the despising of the other, and as such it is not normally used when interacting with patients or labelling their illness. The preferred and acceptable phrases are “*kugula encondvweni*” and “*sifo sengcondvo*.” Transliterated to the English language this term equates to: “illness of the brain” or “disease of the brain”, changing the whole meaning from that of the western medical meaning.

The aim of this study was to obtain an in depth understanding of Swazi women’s experiences and perceptions of recovery from schizophrenia, however, as there is no such word in siSwati this presented a challenge as attaining a high level of equivalence in this instance was impossible. Whilst upholding participants’ original lived experiences in qualitative studies is one of the greatest challenges, this is further complicated when a research study is conducted in one language and then translated and analysed in another language (Regmi et al., 2010).

Even though all participants in this study were identified as having a diagnosis of schizophrenia according to their clinical records, it can be argued that their narration of experiences and perceptions of recovery was based on *kugula kwengcondvo* (being sick in the brain) or *kuhlanya* (madness), or *sifo sengcondvo* (the illness of the brain). In other words, participants are likely to have been describing their experiences of living with *madness* or, *kuhlanya*, as opposed to living with schizophrenia. Furthermore, according to one of the senior nurses at the

SNPH, the majority of patients living with schizophrenia do not know their medical diagnosis. During an informal conversation with one of the nursing sisters at the hospital, she explained that the team agreed not to inform patients of what their diagnosis is, because they assumed that revealing the diagnosis could cause a decline in their mental state. However, one wonders about how their interpretation or understanding of a diagnosis of schizophrenia would be received, given that this word does not exist in siSwati.

In her paper on lessons learned when working with translators and interpreters in research, Phillips (2011) identified one of the constraints I encountered during my study, the lack of qualified translators. I was only aware of one translator and I approached him when I was in Swaziland. This translator is well known in Swaziland, but his expertise is in translating religious documents, because of his experience in biblical studies. Rightfully, he informed me that he was not comfortable to translate mental health studies because of his lack of knowledge in this field. However, on reflection I wondered if his novice status in mental health issues could have served as a positive trait to translation, by facilitating non-polluted interpretation. Another challenge I faced was the issue of literacy amongst the participants. As indicated above, most of the participants interviewed were illiterate and therefore were not in a position to help with back-translating (Temple & Young, 2004; Phillips, 2011).

Regardless of the problems identified above, the interpretation of translated information is influenced by the reader's socio-cultural and linguistic experiences (Phillips, 2011). This compromises the translators' effort to attain a high level of equivalence. In this study the fact that the researcher and participants share the same language and culture served as a strength. Having the dual role of researcher and translator facilitated close interpretation of the



participants' stories, while ensuring every word was accurately translated, along with the cultural implications of phrases and words. As such, a higher degree of equivalence and compatibility of meaning was realised. However, for some, regardless of whether the researcher is the translator or an individual is chosen to undertake this task, does not make much difference, as the important aspect is to ensure objectivity throughout the process of translation (Temple & Young, 2004). However, as alluded to earlier, objectivity is a challenge in qualitative studies; nevertheless, regular supervision and the use of a reflective diary counteracted this constraint (Lopez et al., 2008; Regmi, 2010).

#### **4.6 Translation and Rigour**

The discussion above clearly indicates the complications associated with translation in qualitative studies, specifically in ensuring a high standard of authenticity. A number of authors have made recommendations on how to ensure optimum authenticity within multilingual studies. For example, Van Nes (2010) asserts that during analysis, researchers must adhere to the original data, as much as possible. This could be done by first using the original (siSwati) language to transcribe the recorded interview, before translating it into the English language. Doing this serves as a constant source of reference during analysis, ensuring that the originality of participants' narrative is maintained (Smith, 2008; Ng et al., 2012; Thara, 2012). In this study I adopted this strategy for one of my interviews. However, due to limited time subsequent data were translated to the English language before being transcribed. Additionally, the tape recorded interviews were readily available and predominately used throughout the data analysis in order to ensure that participants' stories remained original (Van Nes, 2010).

The reality of engaging multiple bilingual researchers and translators has financial implications and consumes a lot of time (Temple & Yong, 2004; Smith, 2008; Lee, 2009). However, for the purpose of checking that meaning is not lost during the process of analysis some authors

(Twinn, 1997; Squires, 2009; Van Nes, 2010) recommend that a number of researchers and translators be involved in the process, as a way of ensuring authenticity of the research. As already suggested in Brislin's (1970) strategy, the bilingual researchers work independently then meet to discuss their findings, and to reach a consensus on how best to address the difference in their analysis. Van Nes's (2010) further recommends making notes during the meetings as a way of promoting transparency and justification of any adjustments made during the analysis.

Another strategy I used to promote authenticity in this study is using participants' direct quotes when presenting and discussing the findings (Smith et al., 2009; Van Nes, 2010). This helps the researcher to keep his/her research close to the participants' narratives. Even though this strategy has the potential to distress participants, should they read their narrations (Temple, 2008), their quotes would have to be anonymised and presented in such a way as to protect that anonymity. Also, participants recognising self is perhaps more unlikely as reports, such as this thesis and any subsequent papers, are written in English, a language they do not speak.

## **4.7 Conclusion**

This chapter is important, because it offers the reader transparency in the steps taken to ensure that the knowledge added by this study, regarding the perceptions and experiences of women living with and recovering from mental illness in the African socio-cultural context is authentic. Omitting this chapter could have deprived other scholars of knowing about the challenges I encountered when undertaking this study, and the strategies I used to deal with these. In other words, in following this study, other researcher using multiple languages will be able to critic the strategies from this study, and/or adapt them for their studies accordingly.

On reflection, I have become acutely aware of the impact of language and translation issues within mental health in Swaziland, in terms of ‘medical diagnosis’, perceptions of patients, and how the latter are perceived by health professionals. Perhaps further studies need to be conducted around Swazi health professionals’ perceptions of recovery from schizophrenia, to compare them with the findings from participants in this study. Furthermore, in an attempt to enhance the findings of this research, I have discussed both translation and transliteration in this chapter in an attempt to expose any issues which may have threatened the authenticity and believability of this study (Temple & Young, 2004; Larkin et al, 2007; Squires, 2008).

I felt it is important to include this chapter in my thesis, and before discussing the findings, for the reason that it increases the transparency of the study, and serves to offer important information to other researchers who will be conducting research in more than one language. While the methodology informed my choice of the research, considerations of issues around translation and transliteration have been significant in data collection and analysis, so that this chapter serves as a catalyst for of transparency and truthfulness of my research findings.

# **Chapter 5**

## **Findings**

### **5.1 Introduction**

This chapter presents findings of this research. It details the data analysis, outlining how I generated the resultant thematic issues arising from the interviews, and the outcome of my interpretation of the lived experiences and perceptions of Swazi women living with schizophrenia, and their meaning of recovering from it.

### **5.2 Overview of analysis**

In his book on IPA Smith et al (2009), recommends two ways of writing up the analysis: an idiographic or thematic presentation. He clearly indicates that these can be used according to the researcher's preference and creativity (Smith et al., 2009). In the former the writer presents each participant's themes, as opposed to the latter where all participants' themes are presented together. In this study the results are presented using the latter format. When adopting an IPA approach, it is suggested that the researcher looks at their analysis for subordinate themes which, at a later stage can be coalesced into super-ordinate themes (Smith, 2000). In this study four super-ordinate themes were identified from across all participants' stories, with a number of subordinate themes being inherent within them. However, central to all of the themes identified are the participants' voices and these are fore-grounded within the presentation of these findings.

There is no significance in the order of presenting themes, I have only ordered them this way because I feel this is how they make sense, as well as best answer the research questions.

Brief stories for each participant have been written to promote understanding of each woman lived experiences, and hopefully give the reader a picture of the roots of the themes (appendix P). All names in these stories are not real, but pseudonyms, enabling some insight into the person while keeping anonymity. When writing the stories I debated whether to write in the first person, or second person. I wrote a few of the stories in the third person, then in the first person. I felt more close to their experience when using the first person. Both methods involved my interpretation of participants' actual experiences, and while it could be argued that this process dilutes the originality of their stories, the most important aspect of this exercise is its ability to enhance understanding of participants' lived experience. In other words, writing these stories was a way of promoting understanding of participants' experience; a process that enhances the researcher and reader's further 'sense making' of their 'life world' (Larkin et al, 2006).

This study was designed to explore the perceptions and experiences of Swazi women living with schizophrenia, and their meaning of recovery from this illness. The findings are separated into four sections (super-ordinate themes): (1) The emotionality of the illness of the brain; (2) Pain! Living with the illness and with others; (3) Luhlanya lolu, ungalunaki (she is mad, just ignore her); and finally, (4) Kubancono (Being better). In helping to give context to the findings, table 4 below gives demographic information regarding the participants.

**Table 4 Participants' information**

<b>Pseudonymes</b>	<b>Age</b>	<b>Distance of residence from the SNPH (in miles)</b>	<b>Highest level of education achieved</b>	<b>Year of diagnosis (from records)</b>
Nono	50	26	Std. 2 (4).	2005
Londi	30	8	G. 1 (Recpt.)	2005
Lulu	36	4	None	2001
Eli	56	20	F. 3 (9)	1973
Jojo	50	10	G. 1 (Recpt.)	1989
Thobile	50	15	None	1985
Felaphi	64	13	University degree	1978
Tholu	68	3	Std. 5 (6)	1977
Selina	34	12	F.1 (7)	2006
Tenele	22	10	Std. 4 (5)	2008
Titi	55	9	G.1 (Recpt.)	1975
Pholile	48	10	F. 3 (9)	1995
Winile	48	14	F. 2 (8)	1994
Welile	38	22	F. 5 (11)	1998
Salaphi	51	13	Std. 5 (6)	1990

## 5.3 Identified of themes

### 5.3.1 Sorting and Grouping of Data

Each of the translated interview transcripts were carefully studied in order to ascertain significant issues presented by the interviewees. The first script was read, and reread, while notes and comments were written in the right hand margin. Emergent themes were then written in the left hand margin. All emergent themes were grouped and then further clustering took place to develop the super-ordinate themes. At this stage themes were determined, not merely by the frequency of words or phrases used by the participants', but mainly by the vividness and articulation of their experiences. The clustering process involved abstraction, numeration, subtraction, polarization and function contextualisation (Smith et al., 2009). Themes which were not related to the study were discarded.

*Ideographically analysing subsequent interviews became a challenge, because of my already pre-existing knowledge of the themes from previous scripts. Identifying this was beneficial, as it prompted me to read something completely different as a distraction before analysing the next interview. Some ideas and thoughts, from the previous analysis emerged as I analysed subsequent scripts. Nevertheless, because of my awareness and managing this through distraction techniques I was able to 'bracket' previously identified themes, in order to ensure that all themes related to that particular script were unique to each participant.*

In order to facilitate a vivid cross clustering of all 15 participants' stories, I then cut and pasted relevant themes from all participants, grouping them according to Smith et al (2009) clustering strategies: abstraction, numeration, subtraction, polarization and function contextualisation.

To authenticate findings, when analysing large amounts of data, identifying the reoccurrence of each super-ordinate theme across the participants' transcripts becomes paramount (Smith et al.,

2009). In this study I considered a super-ordinate theme as reoccurring if it was present in more than five participants' transcripts.

*At this stage I realised the importance of having fewer participants. Because of the number of participants in this study, this process was challenging and took a while to put together. If I were to repeat this project, I would reconsider the number of in-depth interviews. Nevertheless, even though I am a novice in using the IPA, I believe this has given me good practice for subsequent research projects.*

The four super-ordinate themes identified in this study are: **The emotionality of the illness of the brain; Pain! Living with the illness and with others; Luhlanya lolu, ungalunaki (She is mad just ignore her); Kubancono (Being better).**

The analysis of the participants' transcripts will be written in the context of each superordinate theme, along with the sub-ordinate themes which contributed to their formulation. Table 5 below shows a summary of subordinate and super ordinate themes from the analysis.



**Table 5 Super-ordinate and subordinate themes**

<b>Sub-ordinate themes</b>	<b>Super-ordinate themes</b>
The illness of the brain Changed self and feelings of rejection and desperation Tension and stress of the experience	<b>The emotionality of the illness of the brain</b>
Family & community, e.g. police Hurt by staff	<b>Pain! Living with the illness and with others</b>
Rejected by Family & segregated by society (tarnished) Discrimination at work/employment Professionals attitudes Seclusion	<b>Luhlanya lolu, ungalunaki (she is mad, just ignore her)</b>
It's up to me Family, significant others, community Hospital Religion Medication (willingly, following the rule) Motivation to overcome Assertive Productivity & contentment Being valued & wanted	<b>Kubancono (Being better)</b>

## **5.4 Overview of Themes: Super Ordinate and Subordinate**

The first theme is ‘**The emotionality of the illness of the brain.**’ At the beginning of their narration, most participants talked about their experience during the first episode of their illness.

They also labelled the mental illness as either ‘the illness of the brain,’ or ‘the illness’ and they defined the illness as that of the brain. Participants expressed a lot of unpleasant emotions, describing their experiences as mainly ‘horrible’, and ‘unpleasant’. Within this theme participants defined the illness of the brain, identified changes experienced as a result of the illness, and expressed feelings of tension and stress; each of these being a subordinate theme.

**The pain of living with the illness and with others.** This is the second super-ordinate theme whereby participants’ stories resonate with a cry relating to the challenges they faced from those around them. In an attempt to help and support them, participants felt their relatives and members of the community were unsupportive and did not behave in a way that they could appreciate. The participants’ felt that those around were not listening to them. They described how, even though they were talking, and at times crying, those around were hearing, but not listening. Instead of helping to support them, participants’ felt ‘dishonoured,’ to such an extent that they believed their rights were infringed. Some participants believed others took advantage of them because of living with the illness of the brain.

**Luhlanya lolu, ungalunaki (she is mad, just ignore her).** Participants talked about their negative experiences from various groups in society, as a result of living with the ‘*illness of the brain*’. They felt that most members of society treated them differently.

While the majority of their experiences were unpleasant, most participants still talked about **Kubancono (Being better)**. This super-ordinate theme indicates a change in the participants’ experience from one of negativism to hopefulness; bringing an improvement and comfortableness to their situation. Within this theme participants’ defined and explained their beliefs about ‘*being better*’. Most of them highlighted some of the things that make them better,

such as spirituality and support from family and some hospital staff. Being fulfilled and the ability to overcome the illness also made them feel better. Even though they acknowledged some of the limitations and adverse changes that have come about as the result of living with the '*illness of the brain*', most participants seemed to choose to dwell on their accomplishments and their potential, thereby bringing a sense of contentment and fulfilling lives.

I have chosen to leave some of the titles of the themes in the native language because I feel this better resonates with the women's experiences in a more vivid way, perhaps reflecting the true value of my findings. For example, the word '*Kubancono*' was used when participants were talking about '*being better*', or recovering from the illness of the brain.

After an idiographic analysis of each participant's scripts I then compared each participant themes with the rest, and then merged them to come up with common subordinate themes. Further coalescing of the subordinate themes then led to the formulation of super-ordinate themes. In this analysis super-ordinate themes will be tabulated with their corresponding subordinate themes, along with participants' quotes. Extracts from my reflective diary will also be included along with the analysis. This will hopefully provide the reader with an insight and understanding into the roots of the themes.

#### **5.4.1 Super-ordinate Theme 1: The emotionality of the illness of the brain**

This super-ordinate theme captures participants' ideas of what they think and how they defined schizophrenia which they named "illness of the brain"; and described the experience of this illness, mainly during its initial phase. The 'illness' appears to be associated with long lasting emotions. Participants were keen to tell their story from the beginning, and as such, defining the illness and describing presenting symptoms. Even though clinical records revealed a

diagnosis of schizophrenia, none of the participants used the word schizophrenia; they referred to the condition using different names, mainly “the illness of the brain” or “the illness.” As such, the phrase illness of the brain or the illness will be used in the remainder of this chapter, and thesis when referring to schizophrenia.

Within this super-ordinate theme, participants described their experiences of living with the illness of the brain. The outstanding features they associated with the illness of the brain are; an awareness of the changed self, feelings of rejection and desperation, and tension and stress. Participants verbalised restrictions, changes in behaviour, as well as conflicts within themselves; due to either hearing voices or seeing things which were not visible to others. In addition to defining their illness and describing what could be construed as symptomatology, most of the participants were keen to share their story of how the illness started. One of the major findings of the first stage of data analysis was the ability of the respondents to recount the events that occurred at the onset of the illness. Along with other experiences, they vividly remembered the interventions taken by their immediate family, community and hospital staff. This overarching super-ordinate theme emerged from a number of subordinate themes discussed below.

#### ***5.4.1.1 The illness of the brain***

Within this sub-ordinate theme participants presented their idea of the meaning of the ‘*illness of the brain*’. The theme captures participants’ emotional experience of living with the illness of the brain, and also encompasses their definition and description of the illness. As discussed in chapter 4, the issue of language has been significant in this study. It is therefore paramount to have an insight into the language used by the participants in order to give meaning of the illness, as opposed to that of the researcher’s interpretation.

Even though, according to clinical records, all of the participants have a diagnosis of schizophrenia, none of them talked about schizophrenia, but referred to the condition as either *‘the illness of the brain,’* or *‘the illness’*.

Salaphi referred to;

*Being ill.....being ill in the brain....I started...presenting..... (1:5)*

Pholile talks about;

*I can say that...since the illness started in 1995..... (1:4)*

Winile informed me; *“I have illness of the brain.”*

*The siSwati language does not have the name schizophrenia. This became a challenge during the interview, such that I found myself hesitating during the interview. Finding the right word in the native language to name the illness “schizophrenia” is impossible; it does not exist in the siSwati language. I would have to repeat ‘schizophrenia’ in English. The problem is participants’ understanding of the labelling diagnosis. From my experience as a Swazi nurse working at the psychiatric hospital, the general public either say the word in English ‘schizophrenia’ or refer it to ‘kugula ngenconvo’, which is transliterated ‘illness of the brain.’*

*The challenge with this transliteration is that it does not specify which illness of the brain, because there are different brain conditions including mental illness. In other words the siSwati language does not allow for the classification of brain illness. This means that participants’ description of recovery could have been based on general mental illness, rather than on schizophrenia. Even though participants’ diagnosis of schizophrenia was in their hospital records, their description of recovery was mainly based on ‘their’ experience with the ‘illness of the brain.’ On reflection, during the interview with Winile, I even ‘put*

*words in her mouth,’ when saying “you have schizophrenia?” (1:6) I then listened to the audio-tape again and noted that after this question Winile kept quiet for a little while before she responded “yes.” It is likely that her response could have been more about telling me what I wanted to hear rather than what she really meant. It is possible that she was never told about her diagnoses of schizophrenia, so that it does not have any meaning to her.*

*When re-listening to the participants’ narration, none of them said the word schizophrenia. On reflection I realised that my experience as a nurse, having worked both in Swaziland and the UK, had an influence on the language I used. I also made an assumption that participants would refer to the illness as stated in their medical records. While I acknowledge it would have been better to ask them to tell me the name they give to the illness they live with, instead of stating this to them, it also shocked me to realise that people can be given a diagnosis of mental illness, and even be treated for it without them knowing. Living in the UK has influenced my perception and behaviour and the lack of knowledge on the part of the participants in this study has made me give more thought to working collaboratively with people who are experiencing and/or recovering from mental illness.*

Winile appears not to be sure about the name of the illness she is being treated for, she said; “*they say my brain gets lost*”(1:5). It is likely that her use of the word “*they*” implies that she feels that the diagnosis was imposed on her. Alternatively, Winile could have used the term ‘*my brain gets lost*’ to indicate her loss of memory for what had happened on her journey to recovery.

Participants explained how the illness started, most of them associating extrinsic antecedent factors with the illness of the brain. However, triggers to Welile's illness are intrinsic and possibly hereditary. Her experience reveals that symptoms started during her childhood, and are similar to those experienced by her brother. She stated;

*I use to suffer from feeling dizzy when I was a child, I could feel dizzy, like when going to the toilet, then I fell, I could wake up and found myself at a different place, and I would do like this..... My elder brother also had this problem too. To me it felt like my brain was being disturbed (4:99-101)*

*I saw things that are not there, my mother took me to Dr H, Dr H told me that my blood level was low, it does not reach my head...he said....he said this makes me ill, he said my mother should bring me here (1:7-9)*

Dr H informed her that she had poor circulation to the brain, probably suggesting that her illness of the brain is associated with a physical condition.

Eli's doctor informed her that the illness was triggered by studying 'very hard';

*Doctors told me that I was studying very hard when the illness started, I was doing form three, and my books got lost just before we wrote the junior certificate examinations in 1973 (15:321-324)*

Even though the doctor informed her of the cause of her illness, Eli seems dissatisfied with the explanation. Soon after talking about the doctor's explanation regarding the cause of her illness she then elaborated on the loss of her books just before writing an external examination (the junior certificate, JC): This is possibly due to her suspicion that her books were stolen and used for witch craft; a possible belief for the cause of the illness. From my general knowledge and experience as a high school student in Swaziland there have been incidents of use of witch craft amongst students, especially during examination time. One student at the school where I did my high school actually confessed that she was given some medicine to put on students' books while they were asleep, in order to disturb them during their studies.

Similar to Eli, Tenele appears to be suspicious of some form of witch craft being related to the cause of her illness. Tenele said that the illness of the brain started after receiving a hand shake from a stranger;

*It all started when I was given a hand shake by an unknown person. I fainted, becoming unconscious for a long time (24:506-509)*

Pholile also talked about unknown people being a trigger for her illness. She said:

*Oh! I was terrified. I was terrified. This was when I returned from church. I saw that there were people coming towards me, these people were fighting. Ye...t, yet what really scared me was that one of the princes wanted me, and I did not want to, I was terrified through him (1:10-13)*

Pholile's experience could have cultural links to what she believes triggered her illness of the brain. She lived at Lobamba, an area dominated by traditional cultural practices. In fact, most of the Swazi traditional ceremonies, such as the reed dance are held around this area. Also, most of the Swazi princes live at Lobamba and it is common for them to have four, five or six wives. When Pholile talked about the onset of her illness she described when coming back from church, she saw people coming towards her and indicated that the actual trigger was articulated when she said; '*what really scared me was that one of the princes wanted me*'. Pholile may have thought the prince wanted her for marriage, and as most Swazis who go to church detest polygamous marriages this idea may have been abhorrent to her. So for Pholile, as one who was coming from church, maybe the thought or experience of the prince's 'wanting' her terrified her to such an extent that it triggered the illness of the brain. The possible use of the word 'wanting' me could also indicate that she had little or no say in the Prince's decision to marry her (a common issue in this context) and this could have made her more terrified, perhaps triggering fear and anxiety.



The triggers for Tholu and Felaphi's illness have to do with broken trust in a previous close relationships: Tholu with her husband and Felaphi with her pastor. Both participants believed the trauma of having their trust betrayed led to an injury or trauma to the brain. Tholu believed:

*"I first got injured in the brain when my husband started having extramarital affairs. This caused a lot of distress to me". (31:656-658)*

Tholu associated the first episode of the illness being a result of an unfaithful husband. For Felaphi she became disappointed and disheartened because her pastor did not support her when she was going through a difficult time;

*"I experienced a great brain injury from my pastor who did not support me when my daughter became pregnant before getting married..... During his home visit, the pastor attributed my daughter's premarital pregnancy to the fact that I was no longer able to attend church, and this really hurt me." (19:397-404)*

In Jojo's experience, the illness started because of endless problems she encountered. She stated;

*"Because these problems make me to be unwell in the brain. I started attending mental health services after I could not sleep during the night. I would hear people talking....none stop..... These people talked a lot of things that made me not to sleep." (1:6-9)*

One of the main challenges for Jojo was scarcity of money, causing her concern as to how she would meet her needs and those of her family. Like all the other participants, Jojo had to go to hospital because the illness changed her behaviours to what was considered socially unacceptable. These will be discussed in the next sub-ordinate theme.

#### ***5.4.1.2 Changed self and feelings of rejection and desperation***

In this sub-ordinate theme, participants talked about how the illness brought about change in them; which included uncontrollable, dehumanising, risky behaviour. As a result of these changes, participants seem to have experienced feelings of rejection and desperation; especially following others responses to this changed self. This sub-ordinate theme captures what participants say about how they presented and interacted with others during the illness.

Most participants talked about changes within the self during an acute phase of the illness.

*This made me think about my own behaviour in developing this analysis, going back and forth to all the steps of the IPA process I had done, made me wonder. I find myself changing the themes, both the super and subordinate themes. I ask myself why I am moving one theme from here to there, how does this answer the research questions, is this relevant, but should I be doing the merging and deleting of themes now, or should I focus on the writing. All this is going through my mind, until I re-read Smith et al's book (2009) that this process is ongoing even during the writing process, the hermeneutic cycle goes on. So at this stage it is important to refer back to the research questions, making sure that the themes identified are relevant to what the study wanted to investigate (Smith et al., 2009).*

Most participants' stories revealed that during the experience of their illness they could not control their behaviour, consequently negatively changing who they are and others' reaction towards them; and necessitating referral to hospital, or to traditional healers, or to be prayed for.

Welile stated:

*"I could wake up and found myself at a different place, and I would do like this (demonstrating something that looked like a convulsion). To me it felt like my brain was being disturbed.....I use to hit my brothers; I could come out of the house naked, run away to the park. My family then took me and brought me here." (4:99-105)*

Although Welile seems to display unacceptable behaviour, her convulsions and being prescribed Epilim, is more in keeping with a diagnosis of epilepsy. Similar to Welile's experience, Eli's story conveyed a sense of uncontrollable and dehumanising behaviour, one that posed risks to self and others, Eli realised that there were changes in her behaviour and at these times her memory became impaired. She said;

*"I remember that I use to undress and walk in public naked, and would wander around aimlessly, I would forget the way home, and instead of going home I found myself in a forest." (15:318-16:323)*

Winile stated;

*"When this illness of the brain starts I lost my strength, my mind gets lost.....I see people coming to me. .... eeeee.....even entering under cars.....you see....people who were coming to slaughter your head.....wanting to stay....alone.....you did not want to be with any one next to you.....I used to run away a lot.....I used to ru.....n....aw.....ay a lot, I used to sleep under cars. I use to beat.....I beat people (moment of silence), I could run away, I did not know where I was going. I could see people coming to kill me. They then took me.....I wanted to be left alone, I did not want to stay with others, I wanted to be alone, I wanted them to lock me alone." (2:30-54)*

Winile's uncontrollable behaviour put her at risk; she was continuously running away, not knowing where she was headed. She wanted to hide under cars, because she said she was running away from the 'people' who wanted to slaughter her. Winile could have wanted to be alone because she might have been low in mood or frightened by the people around her. Her inclination to hide under cars was risky behaviour and could have been fatal. Also, in the first statement above she talks about self in the first and third person, perhaps suggesting initially she was not comfortable talking about this experience, but later gained confidence in self disclosure. Also, while for the most part Winile spoke fluently, during each of the instances above there was a moment of silence, and she stammered at different times. It is possible that this was associated with moments of reliving the past negative experience or she could have been embarrassed in reiterating these events to me.

Salaphi started describing her illness as follows:

*"Being ill.....being being ill in the brain....I started...presenting like someone possessed with animals....just like that." (1:1, 2)*

This is actually a transliteration from the siSwati language, Salaphi said:

*"bengenta njengemuntfu lonetilwane."*

The common meaning of this phrase is that she behaved in an abnormal way, resembling that of animals. She continues to elaborate:

*"I started dancing.....getting out of the house in the night to dance, I was not sleeping....I was hearing voices of people I did not see, the person talking seemed to be my relative, from my mother's side, my grandmother, I was hearing all her voice, clear as when she was still alive..... They then brought me to hospital, it happened that when they were trying to get hold of me I was stubborn, I was very strong, I beat them, they tie me, I beat them." (1:7-13)*

Even though Salaphi's experience of hearing voices is similar to most participants, hers differed in that they did not cause her distress, possibly because these were the familiar voices of her late relatives, instead she put on her dancing clothes, sung and danced. She said:

It could be argued that rather than behaving in an unacceptable manner, Salaphi was rejoicing at hearing her grandmother's voice, perhaps brining back positive memories.

As a result of living with this illness Thobile believes her life has been restricted;

*"I am not able to do what I want, I do not have enough strength, and as a result I am not able to do what I want. My strength has been consumed by the illness." (4:69)*

It seems as if the illness consumed Thobile's physical strength, as well her motivation and/or interest in activities of her daily life. As a result of the many changes that came about through the onset of the illness, participants struggled to control behaviours which were risky and caused them later to experience embarrassment.

#### ***5.4.1.3 Tension and stress of the experiences***

In their narration, more than half of the participants said they had experienced feelings of terror and tension as a result of living with the illness of the brain. Their changed perceptions and behaviour, appeared to elicit the way in which others' reacted to and interacted with them, causing stress and further tension within. Pholile talked about her extreme confusion, when she was walking alone, a similar trigger as the one she experienced during the initial onset of her illness;

*"Then my brain was **confused**, really, really **confused**, this was when I came from church, I was just walking alone, I then felt like my mind was **confused**, usually in the morning, this thing of getting **terrified**, this is how the prince did it, he made it in such a way that he made me breath like the spirit was going to come out, I was so **terrified**,*

*you see. I could see him at times (raised her voice) this was when he was still alive he is dead now.” 1:19-25*

Pholile’s repetition of the words confusion and terrified, along with her change in the tone of voice (suddenly becoming loud), could be an indication that she was reliving the unpleasant experience, with perhaps some of the terror she felt being exemplified in her retelling of the story. Along with her perception of being persecuted, Winile also wanted to be left alone, but also indicated that she wanted to destroy herself:

*“I could see people coming to kill me. They then took me.....I wanted to be left alone, I did not want to stay with others, I wanted to be alone, I wanted them to lock me alone.....they took me to the police station, I ran away, I beat them because I wanted to enter under a moving car.....I wanted to enter under a moving car.....I thought they were going to slaughter my head.....I arrived here.....I was thinking that these people will not give me any help here.....” (1 & 2:52-60)*

It is likely that Winile was low in mood and wanted to commit suicide by placing herself under a moving a car. It is also possible that she preferred to be run over by a car than to experience the torture of being approached by people who wanted to kill her.

While Pholile and Winile held persecutory ideas, Selina seems to have experienced tension within, as a result of debating voices, consequently leading to feelings of stress. This was evidenced during the interview when she felt hot, an experience she had when hearing voices.

She said:

*“When unwell I use to feel hot, hearing people talk at some places, yet there were no people talking. They talked discussing issues..... at times as if they are debating on a topic..... I feel hot. When I ask the person what they are talking about they answered me back.” 10:211-213*

For Thobile the conflict within her came about as a result of hearing two different voices; one saying bad things and another one saying good ones. Each of these voices influenced her daily life, for example having an influence on whether to eat or not. Thobile explained;

*“The problem is that I was hearing voices; one voice was telling me bad things and another one would say kind words. The bad voice would tell me not to eat, saying the food was poisoned, I would then go without food for some days, I would be hungry.”*  
8:158-171

For more than half of the participants hearing voices caused a lot of distress and tension, leading to the further compromise of their physical and mental health.

*Reflection of first super-ordinate theme*

*Hearing the participants’ stories reiterated the importance of knowing and understanding their experience of living with mental illness. If you know and understand their experience you will be in a better position to support them, because you have moved closer to entering their lived world. For me the IPA has been important because, it has given me the opportunity to understand how they make sense of their illness, and to become engrossed in their world. For example, when they talk about how they ran around public places naked I appreciated them for opening up to share this with me, a stranger and it also made me realise some of the embarrassing experiences they have gone through and possibly reduced their self esteem. As a professional I now better understand the importance of working with them in restoring their self worth.*

#### **5.4.2 Super-ordinate Theme 2: Pain! Living with the illness and with others**

The study established that the majority of the participants were unhappy about the treatment they received from those close to them and those who attempted to support them. They experienced abuse, hurt and despondency, from hospital staff, society and family members.

##### **5.4.2.1 Family & community**

Salaphi, Felaphi, Tholu and Winile narrated how they were mistreated by either members of the family and/or their significant others. Salaphi was misunderstood by her husband after she was found by him dancing at her in laws’ homestead.

*“I really don’t know...also, maybe they thought I was sick because I remember dancing to music when the radio was switched on, I used to dance...(she laughed) I don’t know whether they thought I was mad because of my dancing, I don’t know, maybe they thought I shouldn’t have been dancing at my in- law’s homestead, I don’t know (she laughed) I am not sure if they did not expect their daughter in-law to dance at their homestead, I don’t know what was in their mind. I was found by my husband dancing, wearing the dancing gear, I had purchased the gear to use at a traditional wedding;.....between my brother and his wife....they took my dancing gear and hid it, up until today. I want to buy another dancing gear, because I want to continue dancing.”*  
5:117-120

Saphali asked herself whether cultural beliefs influenced her in-laws' interpretation of her behaviour. It is not commonly acceptable for a daughter in-law to dance or express her emotions at her in-laws; hence it is likely that their perception of Salaphi dancing was based on this premise. Also, Salaphi appears to enjoy dancing, and as a hobby it may possibly have been a therapeutic exercise. Her dancing gear (emafahlawane) was confiscated by her in-laws, causing her much upset. Although such 'dancing gear' is commonly used during traditional functions, such as Swazi weddings, it is likely that others would view it as abnormal to wear it on a casual basis, yet for Salaphi it is what she delights in doing, and she is happy to dance to songs on the radio, wearing her dancing gear. Such societal values and beliefs appear to have a negative influence on people's mental wellbeing and in Salaphi's case initiated an admission to the psychiatric hospital.

Salaphi talked about how she was wrongly treated in hospital, while she was not ill. During her assessment Salaphi said she had raised her voice to tell those around her that she did not need treatment because she was well, but nobody listened to her. Those around her assumed that her loudness was an indication of being unwell. She said;

*"I did nothing wrong, you see...my family said I was sick, they said I stripped naked.....accusing me of swearing, doing things I did not do, they said I insulted them.....saying a lot of things I did not do. I was **quiet**.....oh! **they** first took me to the police station.....**they** told them lies. I tried to defend myself by talking to the police, they said **keep quiet** (she started laughing, she continued to laugh when I asked her to clarify why she was laughing, stating) .....I laughed because I knew everything, and **was aware** of everything, I was **not sick**. I listened to them, I **kept quiet**, they gave me an injection, I then slept. They **left** me in the hospital, I was **locked** in, I started crying because I was aware that I was not sick and did not need to be **lock up**, I felt like I was **locked up** for no reason." 3:68-80*

Salaphi was over ruled by those in power and authority. She was defenceless and was then given treatment without her consent. Her word usage, and repetition: *I kept quiet, the left me, I was locked up*, conveyed feelings of sadness. Her laughter during the interview seemed incongruent, but was possibly used as a defence mechanism, to try and cope or cover up her sad feelings.

Salaphi said she was fully aware of everything that was happening to her. She was physically restrained by her relatives whilst she was given traditional treatment. In her text below, as with other participants, she explained that she knows herself better than what others know about her.

*“You see at home there is a traditional healer; she has a hut where the healing clinic is conducted. At home they held me, **forced** me into the hut.....to eat the traditional healing herbs, they smeared the herbs on my mouth while they held me, I did not want to eat their medicine, they smeared it in my mouth, **forced** me to drink the medicine..... they held me like this.....they tied my feet and hands with a rope, and, like this.....my sister in-law is the traditional healer at home. I know myself, and **I know when I am sick**, that time I was not sick at all, I was just being accused of doing something I did not do.” 4:90-93*

Saphali verbalised that she was upset by not being listened to when she told her relatives that she was not ill, instead they forced her to take traditional medicine, which was probably not in keeping with her own values and beliefs. This is seen in her use of non verbal gestures and language (repetition of words). Salaphi demonstrated an attitude of being assertive and being able to stand up for herself and what she believes, she said;

*“Because I was **aware** of everything, they said I was swearing at people, I was swearing at some people who upset me, they **offended** me, I was not supposed to **keep quiet** and let them do as they pleased to me.....What I did was to swear at these people forcing me **to take something I did not want**; they should **not have forced** me to take their medicine.” 4:94-95*

Similar to Salaphi, Felaphi also told of how she was abused by a significant person, her boyfriend;



*“This man became physically aggressive towards me. I refused to marry him at the district office in Kenya as he had recommended. I was also sceptical about not being accepted because I am a Swazi. I unfortunately I became pregnant with this man’s child, I was embarrassed. My boyfriend told me to abort the baby, because he thought nobody would ever marry me. I refused to do an abortion because I did not want to live with feelings of guilt for the rest of my life..... I debated in my mind; I knew that I would not be accepted at church because I fell pregnant before marriage, it was a difficult time.” 20:425-427*

Felaphi said that she realised her boyfriend was not faithful, then opted out of the relationship, especially because she anticipated further challenges in her relationship due to cultural differences. Felaphi had a desire to maintain her integrity, later on she said that she was happy to have adhered to her values. Salaphi and Felaphi’s stories both encompass patriarchal domination issues, where, because of societal influence men have control over women, and can treat them as they please.

Similar to the two participants above Tholu was hurt by her husband. She recounted:

*“I first got injured in the brain when my husband started having extramarital affairs. This caused a lot of distress to me; he took my livestock and gave to the second wife, supplying his prostitutes.” 31:659-661*

Tholu seems more angered by the fact that she was taken advantage of by her husband. He took her cows and gave them to the second wife, possibly paying a dowry. Her use of language shows her anger and distress; she referred to his extramarital partners as ‘prostitutes.’

Before seeking help at the hospital, Winile went to a traditional healer, where she was thoroughly beaten. It is possible that the beating was part of the healer’s ‘therapeutic process,’ getting rid of the ‘evil spirits in her.’

*“When it started I could go to..... traditional healers, they beat me and beat me, then I would come to hospital swollen all over my body. Hawwuuu!!!!!! It was so painful.” 9:240*

#### 5.4.2.2 Hurt by staff

Five participants gave long explanations about how they were physically and psychologically abused by staff. While at the hospital it is assumed that support and protection of the vulnerable would be key however, these participants were mistreated. Tenele became emotional, and started crying as she relived the pain and trauma of her experience. As a result she might have felt belittled, humiliated, and embarrassed.

*“I was beaten by staff in the hospital.....I did not tell anyone about this. They forced me to go to seclusion; I refused to go.....It is okay you can tell matron about this incident. They used a broom to beat me, and it hurt.” (25:537, 539,541-545)*

*When Tenele disclosed this to me I had mixed feelings. Initially I was very angry because of what the staff had done, and I also became emotional as well. However, I held in my tears, because I thought that my joining in would have been unprofessional, and would possibly give Tenele the impression of hopelessness of her traumatic experience. I also felt mortified, and felt that I did not want to be associated with being a nurse. I felt misrepresented by the staff who beat Tenele. Yet, I am encouraged as I do this study, because the added knowledge from this study will be shared with staff at the hospital, and hopefully other projects geared towards supporting and educating staff will be initiated which will result in changing their attitudes and behaviours. I did report this bad practice to the matron with Tenele’s permission.*

After she was given an injection, Pholile felt like she was pulled or being controlled by an external force, making her progress or action slow, and difficult;

*“It felt like I was **drugged**, they just **drugged** me, the injection just **drugged** me. 2:43, 44 .Then they gave me an injection, I was not ill at all. Now this injection makes you feel sleepy, you feel sleepy until it wears off from your body.” 5:130,131*

Pholile was treated without her consent, and was unnecessarily physically restrained. Her repetition of words indicates her feeling of having no control over what was happening to her. Pholile’s voice changed when she stated;

*“I did **tell the doctor** (spoke with a soft voice, with emphases) **told the doctor** that I was not ill. But they continued to hold me and injected me. I **told them** that I was okay.”* 6:166-168

Repetition and emphases of telling people that she was not ill, and no one listening to her gives some indication of her hurt feelings, and/or possible disappointment of being ignored. Mistreatment with medication also caused Pholile to experience side effects, particularly of weight gain, lowering her self esteem even further.

*“I **told them** that I was not ill, they still gave me the injection. Now this injection has made me gain weight, yet my weight was okay.”* 7:174,175

Pholile could not help constantly referring to her experience of how she was wrongly treated.

*“Eh!.....Eh.....I am looking at this thing that happened to me, it really hurt me (her voice became loud). That I was given an injection when I was well, I was not ill. This injection **hurts your life**, you find yourself being **dragged** on the floor. That I was given an injection when I was not ill, this has really hurt me. All along I had no problem, but now I was given this injection, this hurt me.”* 10:287-289

Pholile's narration above depicts feelings of being overpowered, having no control, and treated without respect. Feelings of pain, irreversible hurt were evident in her change of voice, her repetition about this encounter, and her use of words: '*really hurt, dragged on the floor*'. Pholile seem to imply that her progress in life was impeded as a result of being mistreated and going to hospital when she did not need hospital treatment.

Once more, Pholile made another reference to her distress from the mistreatment she received in the past:

*“But the injection just kills you. You know I use to come to the hospital and tell them that I am not okay, I am not okay, I am hungry, and they gave me food and I went back home. This injection made me to swell, I became fat.”* 11:304-307

She gave the impression of being preoccupied with this traumatic experience, evidenced by her desire to talk about this issue. Maybe she hoped that her maltreatment would be dealt with, or perhaps she was happy to have an opportunity to ventilate her feelings.

Towards the end of her story, Pholile mentioned how bad her experience at the hospital was, and that she does want others to go through the same trauma and to reiterate this further she repeats this part of her story;

*“This is my wish as well, that this will never happen again. That I will be given an injection when I am not sick,..... I was not sick..... This injection wasted my time .....it made me feel like I was being dragged on the floor. I felt like I was locked in, yet life was moving, this was a waste of time.”* 12:319,325,326

Similar to Pholile, Salaphi was forcefully taken to hospital and treated without her consent, leaving her with feelings of defencelessness;

*“They brought me to the hospital, and at the hospital they wrote all the things they said.”* 3:72

*“I listened to them, I **kept quiet**, they gave me an injection.... They **left** me in the hospital, I was **locked in**.”* 3:78-80

Salaphi’s facial expression and her tone of voice suddenly changed as she talked about how she was sent to seclusion, for not being able to sleep. Salaphi was probably upset that her inability to sleep was reported by one of the patients in the dormitory, and none of the staff approached her to find out how she could be helped, or if what was reported by her peers was true. She said;

*“I was reported by fellow residents in my dormitory that I was not sleeping; they said I would be talking and singing throughout the night, then the nurses took me to seclusion.”* 8:204-206

As a result of being admitted into hospital, Salaphi said she missed an opportunity of being involved in the community as a rural health motivator. This would have been a good opportunity

to do something that she is passionate about. Salaphi conveyed feelings of regret and despair, and she appeared not to want to dwell on the issue. Salaphi's mood brightened when she started talking about how she helped care for elderly people during one of her previous admissions to hospital.

Like all the participants above, Welile did not have a good experience during her stay in hospital. When asked about her experience at the hospital, the first thing Welile talked about was her encounter with staff. She used exclamation words, possibly denoting the intensity/magnitude of her distasteful and hurtful feelings regarding her hospital experience. During this time Welile sighed, stammered and paused, possibly implying the frustration she felt and the negative feelings she experienced. Perhaps she was disappointed about the treatment received from an institution that is expected to protect and advocate for the vulnerable, more so because the hospital was recommended by the doctor who attended to her when she first became unwell. Welile alleged;

*"I was admitted into hospital. Hay!!! My stay here was not good..... (sighed) when I came here for the first time.....they, they.....they use to beat us (paused) The odals (support staff). Some nurses also joined in and beat us. We are beaten if you were found fighting with another one. They could beat you and lock you into seclusion." 1:13-19*

Welile continued to tell her story of how support staff did not respect patients, mainly evident in their use of language when speaking to them. They used unpleasant, degrading words that made them feel undermined, judged, ridiculed and stigmatised. Welile had paused during her narration earlier. When asked about other things that made her unhappy during her admission to hospital, she quickly responded as she said;

*"One of the members of staff did not say kind words; she was mocking us, ridiculing us, making fun of us, calling us crocket names. She does not work at the out patients department, she is in the wards, she is not a nurse, she is an odaly (support staff)." 1:26-30*

Staff's ability to support patients at the hospital appears to have been hindered by their prejudice towards them. As a result their immediate needs were not addressed. Welile felt that a particular member of staff was cruel, because she called them by 'crocked names'. This has been transliterated from "emagama latjekile" which means staff was giving them labels of names with negative connotations. For example, the staff said that one of the patient's head looked like butter nut.

Welile felt that the member of staff who caused trouble was cruel, and that she was frustrated in herself and projecting her feelings onto the patients, so that the ward was tense whenever she was on duty;

*"She is bad, she talk like this to everyone, she calls us with crocket names, she said to one of us her head looks like a butter nut, she could find you sat with others, she comes and shout, shouts, shouts (raised her voice as she stated each word shout). You will never find her happy like others, she always shouts." 2:33-35*

Welile repeated the word 'shout' several times, becoming louder with each repetition. I could hear the 'shouting' as she told the story. It must really be disturbing to have staff shout while suffering from mental illness, especially because most of the participants talked about hearing voices. This could have made it difficult to live within a noisy ward. Welile said the nurses were informed about the staff's bad behaviour, but she could not remember how it was resolved. Nevertheless, she commented that nurses are 'better', possibly not perfect, but are supportive to a certain extent;

*"We told the nurses. (paused) We told them that she calls us with crocket names; I don't remember what the nurse said. The real nurses are better, the staff nurses are better." 2:39-40*

Welile talked about the injustice of being sent to seclusion, as she had only hit one of her fellow patients in self defence. She seems to think that the other patient who attacked her should have been sent to seclusion, and not her. Welile alleged;

*“For me to be taken to seclusion it was unfair, I was defending myself, I fought with another patient, she offended me and I fought with her.” 2:53*

During her previous recounting of her experience in hospital Welile indicated that she had benefited from the injection she received, and this she repeated several times. Later on in the interview she seemed to relax and was able to open up to talk freely about her awful experiences with fellow patients;

*“Haaaaa....., (shaking her head). I don’t wish to be readmitted here. I have already mentioned this, nobody cares.....haaaaaaaaaaaa. Other patients steal from you. You find that this leads to fights, because someone has taken somebody’s belongings, or one has been offended by the other, in most case it is a liar.” 8:208213*

The last thing she wants is to be readmitted to the psychiatric hospital. Welile emphasised by repeating this statement several times within her story;

*“I don’t wish to be **admitted in this hospital again**, I don’t wish to be admitted ever again!!!!!!!!!!!! It is very difficult in here.” 8:216*

Welile seem to emphasises that the environment at the SNPH did not help her become better, instead she experience unpleasant treatment to the extent that she does not want to be admitted at the hospital ever again.

#### **5.4.3 Super-ordinate Theme 3: Luhanya lolu, ungalunaki (she is mad, just ignore her)**

This super-ordinate theme encapsulates participants’ experience of being dishonoured, discriminated against and stigmatised. Ten participants told their story of how they experienced either segregation at work or in the community, and rejection by family members, and staff at the psychiatric hospital.

#### **5.4.3.1 Tarnished: Rejection by family, Segregation by society**

Most participants encountered segregation from their family members, significant others and some members of society. Participants' behaviour was either misinterpreted by others, or they spread negative rumors about them and their illness. The participants reported receiving labels in society, such that whatever they did was attached to the fact that '*she is mad*'. Some participants were ignored and not listened to by those who were supposed to be supportive.

Pholile acknowledged that she mistakenly took her night medication in the morning. This made her sleepy during the day. Rather than finding out if Pholile was okay, or giving her support, or at least by listening to what she had to say about her sleeping and medication, her mother's uncle spread rumor that Pholile's sleeping pattern was altered, therefore she was mentally unstable. As a result Pholile was forcefully taken to hospital;

*"In the morning I drank my medication, but I confused the medication, then I became very sleepy, I was sleepy" (5:118,119)*

*"They said I am not well I was said to be mad, they told lies about me, stating that I was not sleeping well. They took me to the doctor and told him all this" (5:124-127)*

Pholile was targeted by one lady in the community, who, according to Pholile, misinterpreted her excitement, and did not like her. She detailed;

*"I was only excited that I was going to Manzini to refill my medication, that's all..... But in this area one of the people did not like me, she tortured me and made me to quarrel in this family..... This lady would leave her house to come to mine, and caused trouble; she caused trouble and mocked me." 5:138-141*

Similar to what Pholile's mother's uncle did, this lady also spread rumours that Pholile was '*mad*' only because she burnt the old clothes belonging to her children. It is important to note that in Swaziland it is common and acceptable to get rid of old unwanted clothes by burning them, especially behind one's homestead;



*“.....she just wanted to fight all the time. You know one day I was sorting my children’s clothes; I burnt the ones that were ripped. She started telling everyone, she is mad, she is mad.”(6:148-150)*

Pholile was labelled and known by the community as ‘a mad lady.’ Pholile related how the stigma of living with mental illness did not only affect her, but her children as well. The lady abused them by sending them to do her house work instead of going to school. Pholile stated;

*“Even my child, a little boy, I would think that my child had gone to school, but no she would force my child to stay at home and do chores for her..... and I asked him why he missed school, he told me she was being sent by this lady. .... she would insult me and insult me...she would shout on the other side, saying “this mad lady, this mad lady.” I was then called a mad person. She would provoke me, and provoke me for no reason.... she never stopped; she provoked me and provoked me.” 6:150-158*

Consequently, Pholile was forcefully taken to the psychiatric hospital, where she was given treatment while she was not ill. A lot of unpleasant issues followed, ones which had a dramatic negative impact in Pholile’s life.

*“This lady told the people that I was not well, and they took me in a car and brought me to hospital.” 6:169-170*

*“I used to suffer from headaches because this lady would talk a lot, and she would insult me a lot. Then I could feel my head aching, it feels like it would split, it was hurting..... I could feel that I was getting hurt through this girl.” 7:178-182*

Pholile was also bullied by her step mother. She refused to give her money from her late father’s properties. Pholile portrays her step mother as one who was abusive and unkind to her and her children. She said;

*“I have a step mother, she has my money, she does not want to give it to me..... she tortures you, and does not understand you.....she also **tortures** your children, she **tortures** them. You find that she will take your child, she will take your child and pretend that she loves your child, not that she loves the child, she wants to **use your child** in her home, **her girls sit on beds**, you see, **her children***

*sleep on the bed.....and your child will be working and **serving them**. They **get angry** at my children and **torturer** them.” 7:188; 7:191-197;*

Like Pholile, Salaphi was labeled as mentally unwell for dressing up and visiting places. In her statement below she talked about all the false accusations made by her family;

*“I like going out to visit places, I like dressing up and visiting different places, visiting my friends and other relatives, that is what I did, then they said I am sick, they said I was mad....I never walked naked....I dressed up very well, I did nothing wrong..... they said I stripped naked.....accusing me of swearing, doing things I did not do, they said I insulted them....saying a lot of things I did not do. They brought me to the hospital.” 3:66-69*

Salaphi said she was aware about everything happening around her, and she raised her voice in an attempt to explain to those around her that she did not need to be in hospital, but was forced to keep quiet. Like some of the other participants, Salaphi mentioned that she knows herself better than others, so that hospital staff should have listened to her rather than her accusers.

*“I tried to defend myself by talking to the police, they said **keep quiet**..... I laughed because I knew everything, and **was aware** of everything, I was **not sick**.” 3:74, 75*

Because of stigma, Salaphi related how she was misjudged by her husband, who sometimes called her ‘a mad woman’, for example after disagreeing with him. Salaphi asserts that even though her husband could have benefited from her wise advice, this was hindered by his stereotyping that ‘nothing good could come out of a mad woman’.

*“If you are...maybe arguing with your husband, or you did not speak well with him, he will label you as being mad, even when you advise him wisely, he takes you wrongly, calling you names. My husband sometimes says ‘you mad woman’.” 5:124,129,131;*

Welile indicated that while she feels accepted by some people within her sphere of influence, she was stigmatized by others. Her comment below seem to indicate that there are times when

she is unwell, but once recovered other people continue to misjudge her because she lives with the illness of the brain.

*“Some take me wrongly; they think I am mad all the time.” 4:107*

As of result of the label received from others, Welile feels uncomfortable. She stated;

*“I don’t feel happy; it makes me feel humiliated and uncomfortable.” 5:113*

Welile’s discomfort is particularly evident when having to take her medication when with her friends.

*“I feel embarrassed to take my medication when I am not at home, because I feel others will say, ah! These tablets, what are they for?” 6:146-147*

In the past Welile was not compliant with her medication, this led to a relapse in mental state. She stated;

*“Then I stop taking them, then the illness wakes up.” 6:148*

For Welile, taking medication for the illness of the brain perpetrated being stigmatized by others, as such her desire is to stop taking the medication. Similar to Salaphi, Welile was emotionally abused by her partner, who labeled her ‘a mad woman’, and this infuriated her. She stated:

*“We quarreled with my boyfriend before we separated.....he was telling me that I am a mad women. I was really upset.” 5:143-145*

Welile’s partner’s attitude changed towards her after informing him that she was living with the illness of the brain. During her last visit to his home, her boyfriend ignored her, and instead he bought alcohol and drank the whole bottle while she was watching. Meanwhile, he told her that

she was not supposed to visit because she was not invited. Her boyfriend's gesture of drinking in front of her was possibly a non-verbal of communication that he did not want to see her, and the 'scale of alcohol' (bottle of alcohol) was more important to him than she was;

*"When I visited him he told me that he did not invite me, he then purchased a scale of alcohol, drank all of it in front of me, and walked away." 6:161,162*

This probably brought feelings of embarrassment and humiliation to Welile, and she said:

*"I have separated with this one, I don't want him anymore." 6:165*

Winile also felt that she was not accepted and/or understood by those around her. She also felt that they were pessimistic about her, with some of the other participants sharing similar experiences.

*"Also, other people **don't take me well**, they misunderstand me, **they don't think well of me**." 4:103*

Winile was uncomfortable about the HIV clinic being at the psychiatric hospital. She was worried what people thought about her as she left mental health clinic, then went to the HIV clinic. Winile said;

*"Then I go and collect the ones for HIV, I just wonder to myself, what do people think about me, what type of a person do they think I am." 11:290*

Eli purchased land before her father died. Probably because she is living with the illness of the brain, and her father died, the seller decided to demand his land back. This is probably Swazi nation land, where there is no title deed given after the sale. After purchasing this type of land the seller introduces the new owner to the chief of the area, and that serves as evidence of the sale. Eli felt vulnerable because there was nobody to support her. She stated;

*“I purchased land in 1995, then my father passed away shortly afterwards. The seller took advantage of my father’s death because they discovered that there was nobody to protect me, they want the land back. These people threaten to harm me physically last year.” 17:348-350*

Selina had a child with a man who abandoned them;

*“This could be of great help to me because my... the father of my child is not responsible; he does not take care of my child even though he works.” 12:243-244*

Jojo was worried about being taken advantage of; people took her items for sale on loan, so that her goods ran out without money coming in. As a result she was constantly worried because she was in financial difficulties;

*“Most of the time these people postpone payment, telling me to return for the money after a few days, when I return, they tell me to come back again after another time, this turn to worry me too much.” 2:40-42*

Similar to Welile, because of the stigma associated with the illness of the brain, Thobile lost her marriage

*“I lost my marriage as a result of this illness; I now live with my parents.” 6:109*

Once, Nono was escorted by her relatives (in a car) when she went for her monthly check up at the psychiatric hospital. When she went in, her relatives abandoned her, and she was left stranded at the hospital. She had no money to travel home by bus. She ended up staying in hospital for a couple of days.

*“I had only come to refill my tablets last year, May (2011), but was left by the car that dropped me, they went with the money and I could not bother a bus home. This lead to my unplanned admission in one of the female wards.” 1:2-4*

Her story reveals that she experienced abandonment from her relative and was also incarceration on the part of the hospital staff, because she stayed for a couple of days before being discharged.

It is important to note that in Swaziland people living with mental illness are allowed to access

buses for free, provided they have with them a hospital note. Nono could have been sent home with this note the next day, rather than staying at the hospital for a couple of days.

#### **5.4.3.2 Discrimination at work**

The findings established that some participants were not able to get meaningful employment, resulting in them only being able to engage in small scale economic activities, for example selling vegetables in the market which participants found demeaning. Joblessness and lack of meaningful employment resulted in hopelessness and lack of self-worth. Under employment can be a factor that leads to lack of self-worth (Knight et al., 2003; Tooth et al., 2003). This was reflected in the following participants' statements. Selina stated;

*"I feel that I am not contributing anything to the family and therefore a burden to him because he is working. We turn to have arguments over food because I am not working and therefore not bringing anything to the family. I wish I could work and make some money, especially to be able to take care of my one year old child". 11:231-233*

From her statement above, Selina perceived that the regular disagreement between her and her brother came about because she was not working and could not make any financial contribution to the family. Yet she had an alternative solution to her challenge:

*"I can sell apples, bananas, tomatoes, but I don't have money to start this business. I could start this business if I could have at least E200 (an equivalent of 20 pounds)." 12:238,239*

Even though Selina reported her non supportive partner to social welfare, she felt that very little was done, and as such she continues to experience the humiliation of having no money. Her partner agreed to send her a meagre amount of money, but he does not do this on a regular basis. This is made worse by the fact that Selina also lives with HIV, for which she has to travel to get medicine. Selina is desperate for money to support her needs and those of her baby.

*"I reported him to the social welfare services in town, he promised to give me money to support my child, but he does not give me the money, there have been occasions when he only gave me E100 (10 pounds). This is not enough because I cannot even buy a tin*

*of milk for my baby.....I then spend a lot of time thinking about how I can get money, where and what food I will give my baby. I get frustrated too when I do not have money to collect medication for myself and my child, because not only am I mentally unwell, I am also HIV positive and therefore have to travel to collect medication on monthly basis. All these hinders my being better, this makes my mind not to be stable.” 12:248-258*

Thobile was in full time employment before becoming mentally ill. She seems frustrated that her employer does not want her to resume work. Meanwhile, Thobile indicated that she sleeps a lot, but she asserts that going to work would help in getting rid of this problem. She believes that resuming work would help her overcome the problem of excessive sleeping. Thobile approached her employer asking if she could be allowed to start returning to work gradually, but he is skeptical about her return, perhaps assuming that she will not perform her duties as well as before the illness.

*“I want my employer to allow me to do things gradually, he should not tell me to stop working, but should let me do things at a slower pace. I have spoken to my employer and suggested this, he told me to wait, and thinks that I am still not feeling well. .... if he would let me work at my own pace, I would gradually gain more and more strength. I want to work rather than sitting idly as I am doing at the moment. My employer has not told me when I would be welcomed to go to work.” 4: 80-89*

Thobile resorted to selling fruit and vegetables while waiting for her employer’s response;

*“I want to start small by purchasing a few vegetables and fruits.....I want to start gradually selling fruits, I want to be active and make money before going back to my job.” 5:94-99*

Even though most participants had ideas of, and a desire to start small scale businesses, they continued to face endless constraints. Winile told me that they were taught to make mats at the psychiatric hospital and how she loved hand work. Although she wanted to make mats to sell, she did not have money to buy the material to start her project.

*“I don’t have the money to start, I mean money to buy the starting material, I like making mats, but money is the problem.” 4:112-114*

Her alternative source of income was to grow vegetables, some of which she could eat with her family, and some she could sell. However, the problem was lack of water to irrigate the vegetables, so that all the work done in ploughing would not be wasted. The magnitude of the lack of water is observed when Winile emphasises her wish to do garden work;

*“You see working in the garden could, could help you, so that you can get food, .....food you get is enough for you, a balance diet, .....you can get spinach, those green vegetable, but then we have a problem with water. Water is very far, we are not able to water the plant after plowing in the garden..... **I really wish I could do garden work, awu!!** But the problem is that of the water.” 5:118/122*

Jojo asserts that the illness of the brain was triggered by the amount of problems she had to deal with, mainly lack of employment and money. Consequently, she is preoccupied with how she could make ends meet so she could have her basic needs fulfilled. She worries about where she will find food for the next day. Her small scale business is debilitated by customers taking her goods on loan, and never paying back her money. More worrying for Jojo appears to be the fact that she is the bread winner of her household, because her husband is unwell and cannot go to work. Jojo presented as a woman losing hope, unless urgent support to attend to her immediate, basic needs is provided. Jojo’s spoke of;

*“Food, I struggle to find food, especially broth to go with my porridge (meaning carbohydrates, or starch). In the past, I use to make sleeping and sitting mats, I am unable to do that now. The reason is that I do not have the right shoes (wellingtons) to go to the river so that I can pick the appropriate grass to make the mats.” 1:22-34*

*“I wonder where I will get money to come to hospital on my next visit, because a lot of people took my chickens on loan, they have not paid.” 2:38*

*“The only problem is finding meat to make stew, I need to eat well because I am on medication, if I don’t get proper food then I cannot take my medication, this causes a decline in my mental state. My husband is now retired, his knee was injured at work, but he cannot work anymore.” 2:51-57*

Salaphi worked as a child minder for a professional school teacher. Most child minders in



Swaziland go to the employer's house, to take care of the child or children. Salaphi chose to inform her employer that she was living with the illness of the brain. This was important as she needed to be excused to attend her monthly hospital appointments. However, Salaphi initially faced resistance from her employer, who would not let her go to hospital for monthly reviews. Salaphi did not give up, but persisted until her employer accepted the situation and gave her permission to attend her hospital appointments.

*"At first she was a bit difficult, she was refusing to let me attend the hospital for my monthly visit, but then she later realized that her refusal was not helpful." 7:183*

It is likely that Salaphi's employer stigmatised people living with mental illness, and that her attitude changed because of the information given by Salaphi. Her employer was willing to learn, and she continued to trust Salaphi with taking care of her child. While Salaphi retained her job as a child minder after disclosing her illness, Eli lost her job as a pre-school teacher without justification. According to Eli, her position was given to someone living near the school. This is not an acceptable reason for losing a job, and raises the question as to whether she was the subject of discrimination, perhaps because she is living with the illness of the brain.

*"I have been teaching at a pre-school. I had to stop teaching because another teacher who lives around the area was then employed. I then worked as a cleaner at Impilo." 18:365*

#### **5.4.3.3 Professionals**

This study revealed that a number of participants felt that some professionals were biased when delivering care, especially with regards to using seclusion. Being sent to seclusion was more punitive than therapeutic. The room was unhygienic to live in and those sent to seclusion were not treated with respect. For example they received their food after all the others had been served, and at times they went without food because there was none left. Rather than being used for therapeutic purposes, participants felt seclusion was used to punish them.

Some participants felt that they were not involved when staff were planning their treatment. Instead of listening to them, staff preferred to listen to participants' relatives, or those who accompanied them to hospital. Consequently, participants were not given the right treatment, and this resulted in long term negative effects. As noted above, Pholile and Salaphi were coercively sent to hospital, and treated without consent. Pholile was not treated well by her mother's uncle, and a lady in the community. The doctor at the hospital did not speak with her;

*"The doctor did not speak much to me,... all he knows is that this is a patient, she is mad."*.5:126

Perhaps he assumed that Pholile would not be able to tell him anything reliable because of her mental state, a stereotypical attitude in Swaziland and what could be considered stigmatising behaviour on the part of the doctor. Similarly, the nurse attending to Pholile had no interest in listening to her. She felt that the nurse, like the doctor, was prejudice toward people living with the illness of the brain, an attitude that hinders recovery. By coming to hospital Pholile's progress was compromised as she was unsupported in meeting her needs, and her experience was one of pain and hurt.

*"I did tell the nurse who was giving me an injection that I was not ill. But because I was talking too much trying to defend myself, I think she said, she is shouting, she is ill indeed, she needs the injection. Yet I did not need the injection."* 11:298-300

When Salaphi was taken to the hospital (like Pholile) against her will, her relatives first took her to the police station. Being professionals, perhaps, Salaphi hoped that she was safe with the police, and that she could relate to them what had transpired before she was brought to them. Staff at the police station appeared to hold a stigmatising attitude towards people living with illness of the brain. When she attempted to explain to the police that she had not done anything wrong, they police told her to keep quiet, possibly thinking that she was 'out of her mind,' and would not be able to give reliable information.

*“I tried to defend myself by talking to the police, they said **keep quiet.**” 3:74*

Salaphi seems to show an awareness of professional power and how this can be misused to stigmatise people living with the illness of the brain. Salaphi’s response below seems to be her attempt to refute this attitude.

*“I know myself, and **I know when I am sick**, that time I was not sick at all, I was just being accused of doing something I did not do.” 4:97*

*One of the most alarming things I have learnt from doing this project is the pain of being taken to seclusion. Participants revealed that seclusion is used as punishment, rather than being a therapeutic safe environment. In seclusion, patients’ self worth and esteem are destroyed, because they are shown disrespect, medication given late, and sometimes they did not get food because it was finished by patients in the ward. Seclusion at the psychiatric hospital appears to stigmatise people, with professionals distancing themselves from those that are considered unwell.*

*After having been exposed to prescribing seclusion in the UK, I felt sorry for the patients in Swaziland. Yet, this made me realize the importance of this study. There seem to be no guidelines on the use of seclusion. I say this because, without any discussions or other interventions, some participants reported by fellow patients that they were not able to sleep at night, were taken straight into seclusion. The environment in the seclusion room, as described by the participants, is so appalling to an extent of being uninhabitable by human beings. Poor hygiene posed a high risk of hospital acquired infections. Thinking about human rights and the whole process of seclusion, I realised that professionals are at risk of facing litigation because of infringing patients’ and/or human rights.*

Five participants felt strongly about, what they described as their dreadful experiences in seclusion. Welile was sent to seclusion for fighting with a fellow patient who provoked her. She was very disappointed with the staff, believing they contributed to hindering her process of her recovery, by sending her to another ward and prolonging her hospital stay. Her use of the word ‘they’ implies that the decision was imposed on her;

*“They could bit you and lock you into seclusion.(1:21). ...It was not my fault at all, she provoked me, and I had done nothing to her. They then sent me back to ward 2, yet I was meant to be discharged. I was upset by this.” 3:60-63; 70-78*

Welile asserts that staff made a wrong judgement in sending her to seclusion. It is not clear what happened, or what was done to the other patient who initiated the fight. Maybe this reaction by staff indicates that staff misjudge patients at times, sometimes use coercive in the treatment to patients so that patients are aware that they have ‘power’ over them. Welile described the state of seclusion as follows;

*“Home is much better, I like it at home. I don’t want to come back here again, I don’t want seclusion. I had bad experience, and I don’t like the seclusion. There is no bed in seclusion..... not even given a mattress to sleep on. They just give you blankets, you have to spread them on the floor and sleep on the concrete. It is terrible in winter when it is so cold, you still have to sleep on the cold concrete, it is a terrible place.” 2:47-49*

*“You find that you cannot flush the toilets, there is no water, you cannot wipe yourself, you cannot wash your hands after using the toilet, when they bring the food in you cannot wash your hand when you want to eat, you feel unclean and unhealthy (Long pause).” 1: 21-24*

In keeping with Welile’s experience, Winile also stated that the criteria for being sent to seclusion was fighting with a fellow patient. Winile also did not like seclusion and emphasised;

*“Once you fight with somebody you will be sent to seclusion, where you are not treated well, you don’t even get food, if you do you get it late, after others have eaten, yet you have been hungry all this time.” 8:213-215*

Pholile described seclusion as being like a prison, where one is locked up and left on your own. It is a restricted area, with no stimulation and interaction with others.

*“Ah!!! Seclusion is not nice, nobody likes seclusion.....You see, even though I think it helps, but you see, it makes you feel like you are in prison. You know, **they post** your food through the window, even your medication **they post** through the window, the nurse can see that...ayi...she is okay now to come out and be with others. Otherwise you stay in seclusion.” 3:60-72*

Although Pholile does not elaborate on the posting of the food and medication, she quickly reverted to talking positively about the nurse who decided the time of her release from seclusion. Pholile appears to not want to talk about seclusion as twice during the interview she changed

the topic. Perhaps Pholile feels embarrassed about her seclusion and/or still feels humiliated by having her food and medication ‘*posted*’ and staff not communicating with her. By using the word ‘*even*’ it is likely that she felt medication should have been handled differently than the way staff did during her seclusion.

For the participants in this study seclusion impacted on their emotional wellbeing. For example Winile paused and appeared emotional as she continued telling her story;

*“It is very difficult in here.....you are sent to spend a night in seclusion, alone.”*  
8:217,218

Similar to the other participants, Winile talked about the physical and psychological hurt and pain of being sent to seclusion. Below Winile described how she was ‘*thrown*’ into seclusion, giving rise to thoughts of it being used as a way of getting rid of her. Overall, seclusion was a hindrance to her recovery;

*“It is painful to be sent to seclusion....there is no mattress, no blankets, you sleep on concrete. They only open for you after everybody has eaten. Medication is brought to you at a certain time; you don’t receive proper care when you are in seclusion.”* 8:220-223

*“Ha!!!!!!!!!!they took me and threw me in seclusion.They came to say hi to me.....I stayed in seclusion for two days. Ahhhh.....I don’t miss this place!!!!!!!!!! I don’t want to be readmitted here again.”* 8:225-230

In seclusion Salaphi also slept on the floor where she felt cold. Furthermore, She was chemically restrained which made her unable to call for staff’s help. Salaphi became very thirsty, as no water was available in seclusion, leading to her drinking from the water in the toilet.

*“It was bad, they made me to sleep in seclusion, I slept in seclusion.....oh!! it was not easy.....I slept on the floor, it was cold, and there is nothing in seclusion, not even a mattress. When I was thirsty I drank from the toilet, there was no water, I drank from the water inside the toilet, I could not shout for help because I was drunk.... because of the medication. It was a difficult experience.” 8:203-212*

Salaphi said she heard voices that told her not to eat because the food was poisoned. Further distress and humiliation could have been perpetrated by staff’s laughter when she informed them that the food was poisoned

*“They brought me food the next day. They put beetroot, you see, I took the food, I talked to myself, they have put the medication on the food, I ate a beat, picking up the one I felt was not poisoned.....they took the food and asked me why I did not eat, I said it was poisoned, they laughed.” 8:219;*

#### **5.4.4 Super-ordinate Theme 4: Kubancono (Feel better)**

This super-ordinate theme captures participants meaning of ‘kubanconco,’ being better. While participants went through challenging times because of living with the illness of the brain, all but one talked about how they felt supported by some of their family members, friends, acquaintances, religious activities and hospital staff. Most participants believed recovery can only be defined by an individual, and emphasised that they know themselves better than anyone else and they are aware when symptoms of the illness start.

##### **5.4.4.1 It’s up to me**

A number of participants contend that being better is unique to each person, and can only be defined by the individual who experiences it. Others said being better is a process, suggesting it is not an either or situation, being ill or being well, but one that has fluidity. According to Winile, being better is a feeling that can only be defined by her, and others are not able to describe her as being better. She stated;

*“Feeling better is when I feel that I am better.” 1:13; 1:25, 27, 28*

Nono recounted being better as a process;

*“My last proper admission was in 2009, at that time **I was really not feeling** well, that was the last time I was not feeling well, I have recovered ever since.” 1:7, 8*

Salaphi also emphasised that she is aware of herself and can tell when well or unwell;

*“I know myself, and **I know when I am sick**, that time I was not sick at all.....” 4:97*

Pholile stated, because of her self-awareness and knowledge of her illness, she is compliant with her medication;

*“I know my illness. I know myself. I know the importance of taking my medication, and I don’t want to die because I have my children. So I don’t know why they forced me to get that injection. I take my medication properly.” 12:320-322*

Thobile asserts that non compliance, along with going through stressful moments led to her becoming unwell;

*“I relapsed because I stopped taking my medication for two months, I thought I was cured from the illness, this made me to relapse.....I was readmitted.....I was stressed by the death of my grandchild and became worried about his death, yet at that time I was not taking my medication.” 6:112*

Winile defined her being better based on the absence of symptoms of the illness, she felt that she behaved in an acceptable way, and was no longer a risk to self and/or others;

*“EEEE...yes, like entering under the car, or beating people who were trying to help me, taking me in a taxi, I would go out and run all over the bus rank, because I was running away from people who were going to cut my head. I don’t do that anymore.” 9:251-254*

The majority of participants said they felt better when engaging in various activities, including work, either at home or in the community. They indicated that they had made the choice and had the motivation to engage in activities. Salaphi and her peers at the hospital worked together, with a goal of moving on to the community:

*“We all worked so that we get better and be discharged from hospital.” 2:35, 36*

Winile said;

*“I am able to do other jobs; this means that I am better now.” 2:37*

Eli defined being better by the restoration of her basic life skills; she is able to self care, possibly restoring her self-worth because she now behaves in a socially acceptable manner;

*“I am better when I am able to do various things, I respect myself not stripping naked in public, being able to bath myself and being able to do a lot of things.” 15:317318*

Nono described being better in relation to working or being productive, and giving support to others. Her mood has now changed; she is more tolerant of others. For Nono, her recovery is enhanced by how others behave; her husband does not smoke or drink, and this, apparently, makes her live in harmony with her husband;

*“It means my life is much better than how it was in the past. Just like I feel now, I can do a lot of work now; I am now able to cut grass (straws) and can use this to make mats; I am taking care of my little grandson, about one year old; I am not irritable; my husband does not drink nor smoke, we live together in peace and harmony.” 1:14-18*

Selina said that she is better because she can now do the jobs she performed before becoming unwell, indicating she has now returned to being ‘normal’ again. Selina recognises that she feels better because she eats, yet does not have to buy the food, perhaps relieving her financial burden.

*“Being better is feeling better, being able to perform duties that you could not do when unwell.” 10:210 “Eating food makes me feel better; I do not have to buy the food. I am happy that I live with my family rather than independently.” 13:272-275*

Lulu said;

*“This is like when a person stops responding to unseen things.....I.....I....do not talk to myself any longer.” 36:771 “I am now able to clean the house..... In the past I used to write aimlessly, I don’t even know what I was writing. I do not do that anymore.” 37:773-775*



Titi's face became bright as she stated;

*"I enjoy doing hand craft. I use to make bags from 'halibhom' (a special green white threaded plant)." 35:739*

Two of the participants explained that recovery is a journey. Thobile's comments below seem to indicate that although she felt better and now able to help her children; her desire was to resume her job as a gardener. Thobile suggested she still needs energy, or maybe motivation to work, something that has been lacking during the illness. Her lack of strength could have been due to the side effects of the medication. On the other hand, Thobile's comment could indicate the illness drained her of physical, psychological and/or emotional energy;

*"I desire to feel better, because I will be able to help my children as much as I want. I desire to go back to work; I use to work, but am not able to now. I worked as a gardener, ploughing vegetables." 4: 65-71*

*"I am not able to do what I want, I do not have enough strength, and as a result I am not able to do what I want. My strength has been consumed by the illness." 4:69-71*

When supported by staff with activities of daily living, Thobile declared;

*".....gradually I realised the importance of bathing as I became better, we were well taken care of at this hospital." 7:146-154*

Earlier on in her narration, and from her statement above, Thobile indicated that the experience of recovery is a process, and while she encountered setbacks regarding her recovery, she was determined to do things gradually as she journeyed through her recovery. As a process, Thobile seem to find it beneficial in the sense that an accomplishment of one task gives momentum to accomplish the next and subsequent ones. To illustrate her definition of recovery as a process, Thobile used a metaphor of taking baby steps;

*"the best way is to do things gradually, starting small would make me to gain more and more strength as I continue to perform duties in small, taking baby steps." (4:73-75)*

Felaphi also indicated that she had not yet fully recovered, possibly because of the magnitude of what she believes triggered the illness of the brain. Felaphi seems to believe that the severity of her ‘injury’ is hindering her recovery;

*“I have not been able to recover well from the illness of the brain. I experienced a great brain injury.” 19:397*

Londi is the only participant who felt that being better is impossible. Londi talked about her admission to hospital, but did not relate this to the illness of the brain. She enjoyed her stay at the hospital, because she had an opportunity to see her boyfriend. According to Londi, the only challenge she had was not having cigarettes, but she was resilient enough to find some, and to ensure that her immediate need was fulfilled. Regarding her hospital visit on the day of the interview, Londi stated that she did not need to come to hospital, but was sent by her mother, who had informed her that she was unwell. She stated;

*“There is no such thing as becoming better. I have never been unwell. My mother is responsible for this. While I was at home mum told me that I should go to hospital. When I left home today, she told me that I am unwell.” 41:866- 868*

Like Salaphi and Pholile, Londi’s blame of her mother for sending her to hospital is an attempt to say that she knows herself better than others, and is therefore in the best position to judge when she is unwell, rather than being told by somebody else.

#### **5.4.4.2 Family and community input**

Almost all the participants acknowledged the important role played by both their families and members of the community in their recovery process. When she first became mentally unwell

Pholile recounted;

*“I found that my small grandmother is educated and is use to hospital..... This really helped. They took me to Nazarene hospital, and there they transferred me here. I found that it was very good; I realized that I became better immediately.” 1:5-8*

Selina received financial support from her sister, and her mother provided her with food and also encouraged her to comply with her medication. She stated;

*“My sister once gave me money to start selling the fruits and vegetable, however, I was tempted to use the money to buy powdered milk for my baby. I used the E100 that I was given by my sister to buy powdered milk for my baby, I therefore had no money to stoke the vegetables as I had intended.” 14:298- 300*

*“My mother encourages me to drink my medication, she reminds me to take my medication at the right time.” 11:229*

Tenele also felt that her family regularly supported her in meeting her basic needs of daily living, including financial support;

*“I live with my mother and sisters. My mother provides me with food; she takes good care of me. My mother gives me food even at night when I feel hungry. My sisters support me financially; this pays for my transport when I come to hospital for monthly check up, and for my fare going to church.” 24:515-518*

Felaphi’s daughter was very supportive of her, financially and otherwise, such that it took away a lot of worry and stress in her mind. The excitement and confidence was seen in her face, and heard in her voice as she said;

*“My daughter helped me finish building my house, she bought me a tank to store water, she wired my house, and I now have electricity in the house; she buys me clothes, where could I be if I had aborted her. I am meeting my daughter today; I am so excited because I know she will give me something; food, money or anything that will make me happy.” 21:430-4345*

Felaphi’s comment below indicates her desire to be at peace with people in the community and to accepted those things that she cannot change. Additionally, she seems to obtain comfort by focusing on the good things in her life, including her past accomplishments and the success of her children;

*“I have no problem with people in the community. I live in peace with them. I do not mind about minor issues with others who are jealous because I am highly educated, that does not bother me. My children have been doing very well with their academic work,*

*two of them are presently studying at the university, one of them was amongst the top fifty best students in Swaziland, I am very proud of them.” 23:478*

Similar to Felaphi, Eli reiterated the importance of tranquillity at home, as a significant contributing factor in making her feel better. Unlike the noise and busyness of the hospital, Eli enjoys psychological calmness, in terms of having good relationship with others, and/or the actual physical peace where there is absence of noise in the environment;

*“I stay at home in peace.” 17:347*

Tholu and Pholile emphasised the value of being visited by family in hospital. From Pholile’s point of view, there is no substitute for family support during difficult times;

*“When my children came to visit me at the hospital they were very excited to see great improvement.” 32: 688*

According to Pholile;

*“Nurses..... bring your parent in, they let her come to visit. They allow your mother to visit you, they take good care, they make you well.” 3:80-81*

Pholile seems to have been reassured by the staff’s positive attitude towards her mother visiting her, such that she felt treated fairly and equal like the rest of the patients. Although Winile indicated that she was not accepted by some people in her community and family, she turned to focus, by elaborating in her narration, on the benefits she received from those who accepted her. She cheerfully talked about how she received genuine comfort and encouragement from them. Winile said;

*“Others accept me, we laugh when talking about my illness, they say I do not live with illness of the brain, they say I am not telling the truth. When I tell them that I suffer from illness of the brain, they say you are not ill, you are joking, then we laugh.*

*Indeed, my friends, and my relatives have accepted me, I also feel that I am part of them.” 5:131,135*

Winile also felt comfortable with her neighbours and family, such that she was encouraged to talk about the illness, and this prevented a relapse in Winile's mental state;

*"We are able to talk, or maybe when I feel that the illness is about to start, you see, then I chat with those that accept me, we talk with them, then I feel better. My neighbours' and my relatives, for example, my sisters and my sisters in law. They accept me, I feel very comfortable and happy when with them, they encourage me until I feel convinced inside me that indeed, I am better now. I feel that they completely accept me; they make me feel like I am like them." 6:149-154*

Salaphi made statements similar to those of Winile, above. She delights in talking with others and she avoids isolation. Besides finding pleasure in spending time with others, Salaphi finds it therapeutic as she feels accepted and valued by members of the community, helping her to forget that she is 'living with the illness of the brain.'

*"I talk to people, I don't stay alone, we talk to other members of the community.....we chat. For an example at home, I live with my sisters in law we visit each other and we chat, then I get preoccupied with this, and I forget that I am living with illness of the brain. I love talking and chatting, we chat with my neighbours as well.....I enjoy chatting with others. I don't like visiting people's homesteads, but they just come to me and we chat at my house, I love people." 8:227-229*

Welile emphasized that, because of the support she received, she prefers to be at home than to be admitted to the mental hospital, moreover she has been in the community, taking her medication for four years, without needing hospital admission. Her statement below revealed her confidence, pride and contentment at living at home. This is reflected in her repetition of being at home throughout her story;

*"Home is much better, I like it at home. I don't want to come back here again." 2:4749;*  
*".....because I stayed 4 years at home, okay...I was eating the tablets and getting my injection, but I was not readmitted, so it is possible to get better." 5: 123-125*

Welile also said that she valued the guidance, given to her by her family;

*“I listen to them, when they say Welile....stay at home, don’t go, I listen, In the forest I do not have anywhere to go. I listen to what they tell me to do at home.” 6:144*

Similar to Welile, Thobile and Tenele also said their recovery is based on the fact that they received adequate family support, and this helped them to cope when going through difficult times. Welile said;

*“What has promoted my recovery at home is that I have no stress, I am not frustrated, and you must not live in a stressful home.” 7:136*

Nono appreciated her husband’s suggestion to balance work with rest, as similar advice was given by the nurse;

*“Although he encourages me to work, he also advised me to take breaks, he says that over working myself can trigger mental illness.” 2:42*

For the majority of participants, family support was highlighted as important both during admission to hospital and at home, on a daily bases.

#### **5.4.4.3 Hospital staff**

A number of participants appreciated the support they received from professional staff, during their hospitalisation and as an outpatient. The support received included relearning social skills affected by their illness of the brain, being listened to, information and support with basic needs and with medication. Most participants’ comments about support given by staff were positive; they felt valued and accepted, as *‘normal people’*.

Titi said;

*“People in this hospital are good, even in the wards everything is alright.” 35:747*

Salaphi alluded;

*“Oh the nurses here are so good, they took good care of us; it was so good, we were well taken care of, those people are so good.” 7:188,189*

Felaphi said she was impressed by nurses’ vigilance, in observing a change in her mental state, and this led to an immediate intervention that prevented further decline;

*“During my admission in hospital, nurses were observant, they realised that I had a disturbed sleeping pattern and gave me medication that helped me to sleep; this made me to be more stable in the brain. I wonder how they saw this, and I realised that nurses and staff at this hospital are caring.” 22:469-472*

In contrast to Welile, who was sent to seclusion for not being able to sleep, Felaphi appreciated that staff were vigilant enough to notice that she was not sleeping well, and gave her medication which helped her to sleep.

Pholile claimed nurses showed both conditional and unconditional love, repeating this several times in her narration;

*“The nurse had love with you, especially when you listen.” 2:51. “There is so much love, the nurse have love. The nurses have love...” 3:77*

Even though Pholile was unhappy with staff’s lack of support when she was wrongly brought to hospital, she appreciated the fact that she was still accepted and understood by some members of staff. She probably felt valued and respected by staff. Pholile attributed her recovery, when she was admitted in hospital, to the fact that nurses welcomed her mother to visit her. Her narration seems to imply that there is no substitute for the value attached to being visited by her mother while at the hospital;

*“It made me feel much better, because when the others have visitors and you don’t, you end up becoming ill, you become ill, even though you are in hospital, you become unwell. They try giving you medication, but you become unwell, you still become unwell. Your heart needs its own things.....yes the body also needs what belongs to it,*

*I can just say God's spirit needs its own thing. The body needs its own thing, it needs love, and when your relatives visit, it really feels good."* 4:97-103

Thobile was assisted and empowered by staff to self care when unwell. She gradually relearnt these previously lost skills, and this gave her confidence. She appreciated staff's support and care commenting;

*"I could not bath myself; the nurses enlighten me about the importance of having a bath on daily bases. The nurses helped us have a bath, we washed ourselves..... Gradually I realised the importance of bathing as I became better, we were well take care of at this hospital."* (7:132-148)

A number of participants valued the time they spent with staff at the psychiatric hospital; where staff provided them with an opportunity to talk or write about their journey and aspirations, or engaged in other activities with them. During some sessions, participants said they learnt a number of things regarding healthy living. Welile said;

*"Sometimes we were given education, they could chat with us...talks about being clean, and....about malaria.....talks on.....eh....cancer...cancer of the womb..... We could sit down and they talked to us about these things. When I was admitted there were student nurses, they would talk to us about these things."* 4:85-89

Thobile talked with staff about dealing with hearing voices;

*"..... I told them everything I heard and saw. The hospital staff's advice on how to deal with the voices and seeing things was very beneficial to me. I was given medication in the form of tablets, these voices and seeing things that are not there. I do not hear voices anymore and I have stopped seeing lions, snakes and fierce animals. I now have normal dreams."* 8:166-169

Lulu said;

*"I also benefited from talking to a certain lady, a member of staff from ward "* (4. 38:804),

Salaphi indicated;

*"Nurses spent some time talking with us, they did.....eheeee, what is it called..... Yes, yes, yes, that is what they called it....this helped me a lot (her voice became louder)....this nurse.....what is her name (quiet, thinking for a moment).....this nurse*



*was so good, she could teach us things, she listened and spent some time with me. A few of us were taken out of the ward to another place where we had the freedom to talk to the nurse. We also had to write on some provided papers, it was so good.” 1:23-30*

Along with support in meeting self-care needs, Welile also said that she was given the opportunity to relearn basic skills which had been affected by the illness of the brain;

*“The nurses gave us food, they looked at how we made the beds and helped us when we were struggling, making sure that we had a bath. There are good showers to have a bath, the water is hot. When the hot water is finished, I could get hot water from the kitchen, put in a bucket, dilute with cold water, and have a bath.” 4:84-86*

Winile learnt a new skill during her hospitalization, that of starting a business of making mats, in order to generate income;

*“E.... eee, also, at the hospital they taught us how to do hand work (expressed with enthusiasm, her voice full of excitement). They taught us how to make mats, you see, hand work.” 4:110-111*

Salaphi reported that her recovery was not ‘instant’; rather, she progressively became better as she continued to engage with hospital staff, a possible indication that her self-worth was gradually restored. Salaphi recounted;

*“Even though I did not feel better instantly, it was the very good, we wrote about how we came to the hospital, how we became unwell.....and how we recovered.....just that time spent on us with a professional, it made me feel important and valued.” 2:32-40*

Having experienced the trauma of being ignored by those who forcefully brought Salaphi to hospital, being listened to by the nurse meant a lot to her, especially, as she mentioned that she was chosen to go out of the ward where she enjoyed the nurse’s undivided attention as she listened to what Salaphi wanted to say, possibly facilitating her sense of self-worth. Salaphi made an analogy of the time spent talking with the nurse to the session she had with myself as

researcher. This possibly indicated that the time spent listening to her story, during the data collection interview, was therapeutic. She said;

*“Just like now, our mission, ambitions and we had time to chat. Just like now where we talk to you, this is similar to what we did, it was good. Interview contributed to my recovery.” 2:35, 36*

Nono benefited from talking to staff about the loss of a loved one. Nono said that she was able to grieve and to move on, accepting what she has. She also reiterated similar feelings to those expressed by Salaphi, comparing the experience of talking with a member of staff at the hospital with the session we had during data collection;

*“and I also talked with another nurse where I discussed my feelings and stress. This nurse talks like you, I had just lost my grandchildren’s grandmother, I was really worried and grieving as a result of this loss. I was also worried about these grandchildren. The nurse helped me to realise that I could still appreciate the children rather than grieve over the loss.” 1:21-23*

Eli appreciated the improvement she saw at the hospital, especially regarding patients-staff interactions;

*“The service provided by this hospital has greatly improved. Before this hospital was opened, treatment was not so good. Staff use to shout at us and beat us at times, it was terrible. Now we are treated very well, I am happy about it.” 16:338-342*

Pholile, like other participants was not happy to be shouted at. When unwell, Pholile believes that one’s ‘reasoning becomes similar to that of a child’ therefore, Pholile suggests nurses must use an acceptable way of shouting, one that guides and encourages good reasoning;

*“They take you like a person who is well. As you could do to a normal person, if you do anything wrong they will shout at you, just like you would to a normal person. They do need to shout at you sometimes, because the mind seem like it will get lost. You go back to become like a child, you just think like a child. Then you go back to be normal.” 3:82-87*

Two participants offered recommendations of how best the psychiatric hospital could be improved. Following her unpleasant experience of receiving treatment when she was well, Pholile recommended;

*“I want the staff at the hospital to listen to patients, not to just inject them without listening.” 11:313*

As a way of reducing the stress and strain of spending their merge finances in travelling to the psychiatric hospital every month, Selina suggested;

*“I wish staff from the hospital could supply us with a monthly medication at an area closer to our homesteads, to the local community meeting hall, rather than us having to come to the hospital every month.” 14:179-292*

#### **5.4.4.4 Medication and support with basic needs**

The majority of participants (more than half) talked about the importance of taking medication in promoting their recovery from illness of the brain. A number of participants indicated that taking medication was not the only thing that enhanced their ‘*being better*’, but it needed to be coupled with other enhancers, such as taking food and prayer. They valued nurses’ demonstration of the importance of being punctual in giving them their medication, and also teaching them about its importance. Such affirmations included Nono;

*“Staff at the hospital we giving the tablets,” 1:21*

Selina;

*“The tablets have been very helpful.” 11:218*

Thobile;

*“The medication is very good, taking my medication has helped me a lot, the tablets helped me to recover from my illness, and I only stayed in this hospital for a month. I do not have any problem with my medication, it is very good. I take my tablets twice a day, morning and evening.” 5:105- 5:106*

*“When I take my medication continuously, I do not relapse. I do not want to stop taking my tablets.” 6:122*

Tenele appreciated both medication and prayers, indicating that they contributed to her recovery;

*“The medication has been very helpful to me I have also been prayed for, that has promoted my recovery from mental illness. A certain pastor prayed for me.” 24:509,510*

Salaphi;

*“The nurses were supportive they gave us medication on time every day... they waited, woke us up when we were asleep, they were patient with us. They taught us about the importance of taking medication on time... They they say you must not take the medication in an empty stomach.....” 2:45-49*

Winile;

*“It’s the tablets and the injection. The injection helped me a lot, because after getting it I slept right through, when I woke I up felt better, I was absolutely healed.” 4:109*

Whilst they appreciated taking medication, a few participants expressed a sense of duty when doing so, possibly implying they were not happy about taking medication , maybe because they experienced side effects. Pholile said;

*“I could say....it helped me that.....that I got the injection, and that I listened to what the nurses were saying, because after you get the injection you want to eat, you were able to eat.” 2:48;*

Winile seem to be doubtful or possibly not at ease about the advice she received, but appears to accept the doctor has the right to prescribe medication, and her responsibility is it to accept it, regardless of how she felt or reacted to the medication.

*“Awwuu!!! They advised me that I should not stop taking the medication for the rest of my life, because if I stop taking them, the illness will come back again. I have told myself, indeed that my life is in the doctors’ hands.” 1:17*

*My recovery is associated with my ability to stick to the doctor’s rules, I take the medication as prescribed, I take the injection....they called my sisters and explained to them that for me to recover you must not take her to traditional healers 9:234-237*

However, while the ‘rules’ are not to take her to traditional healers; Winile says she became better after drinking “clay pots”, this is a transliteration of ‘traditional medication.’ Unlike medication from hospital which has rules, Winile appears to appreciate the clay pots, because of the liberty to take them as desired;

*“Timbita. I don’t know where they take them from, but I can see the difference when I drink it, I feel better. There is no measurement to measure how much I take, and I can take it, I take at any time, and any amount.” 4:93,107, 108*

While prescribed medication has helped a number of participants, traditional healing, for some, has contributed to their recovery.

#### **5.4.4.5 Religious Beliefs**

For most participants’ church and being prayed for played an important role in their recovery process. Being valued and finding satisfaction in sharing their problems with others were important aspects of their recovery. This enabled them to feel that there were people who cared for them and therefore there was something worth living for. Participants’ assert that their trust in a supernatural being (God) makes them better because they feel someone is listening to them, and from this they are able to achieve a sense of hope that their problems would be resolved.

Nono joined a church where she felt she had a sense of belonging and being valued; and where she benefitted from attending prayer meeting and church services;

*“.....I joined a Christian church in my community; I received so much help there as well. I attend church there; I clean the church, and attend prayer meetings every Mondays where I pray with other members of the church, they pray with me, I feel better. I share my problems with my church members and return days or weeks later to share how the prayers were answered.” 3:49-53*

Eli's trust in the supernatural being makes her feel better, along with her interaction with church member;

*"My relatives took me to people who prayed for me, I think that helped me a lot."* 16:331,332

*"I asked people at church to pray with me, this did not disturb me much ever since. At church I share my burden and problems with people there, they pray and encourage me, I continue to trust in the Lord for the solution of my problems. I feel mental well when I pray, trusting that God hears my prayers."* 17:351- 356

Both Tenele and Eli were taken by their relative to be prayed for. They appear to be in agreement with their decision, a possible indication that this was their wish too. Tenele said;

*"My relatives sent me to be prayed for by a pastor, I then became conscious and normal."* 24:505

Pholile received prayers at church, and experienced some relieve from the symptoms of the illness. She still had hope that her problems would be completely resolved. Her trust in the supernatural being seems to instil feeling of hope and reassurance for a much better future;

*"I even went to church to request for prayers. The illness was a little better after the prayers, for about 10 months."* 1:16, 17

*"There, regarding that, I have asked God's servant, and the church to pray for me. You just hung up to the cross; I am looking unto the King to fight for me."* 8:204,229

*"..... I get a lot of support from the church, like the church I go to, at pastor Joko"* 10:278-279

Welile revealed that prayer and attending church is therapeutic for her, specifically when she feels low in mood;

*"When I feel sad, I prefer to pray. I attend a church called Metropolitan, I feel much better there, at Fairview, with pastor JJ ."* 5:114-119

Although two participants (Lulu and Salaphi) acknowledged the importance of going to church, they reported that they were not as active as they had been in the past. They expressed a desire to resume attending, because they recalled some of the benefits of attending. Lulu confessed;

*“I used to attend church in the past, I don’t any more. I am now lazy to go. I used to feel refreshed when I came back from church. I would like to start going to church again starting from this coming week. I enjoyed the youth program and activities on Saturdays. I will start attending the youth program this coming week-end.” 38:797801*

Salaphi also enjoyed the company of others and benefited from being prayed for by other church members;

*“I do agree about this, but I have not been to church in a long time. I might start going again later. I like going to church in the past because we read the word, and we could share our problems with members of the church and they could pray for you. By the time I returned home I would be feeling good physical and emotional.” 10:272*

Winile was the only participant who mentioned that she did not benefit from being prayed for;

*“then they took me to people who prayed....nothing even helped.” 3:60*

She was then brought into hospital where her condition improved. At the hospital her relatives were advised not to take her to be prayed for, and/or to traditional healers. Later on during the interview, when asked to talk about her religious values, Winile briefly responded, and said quietly;

*“I do go to church.” (9:247)*

It is likely that she reacted this way because she was disappointed that she did not become better after being prayed for.

#### **5.4.4.5 Motivation/Determination to overcome**

Most participants talked about how they were motivated and determined to fight the challenges they faced as they went through the journey of recovery from the illness of the brain. Some had to deal with the side effects from the medication, others with stigma, and others had to endure financial challenges. Pholile’s narration below indicates her ability to persevere through the effects of medication. The medication possibly suppressed her motivation and strength to

engage in activities of daily living, yet she confessed that after some rest, she could regain her strength and feel better;

*“You get home and sleep, you feel pressured, you sleep, you sleep, and then you become better like the others, you become better like the others.” 4:92*

Salaphi seemed content and confident in herself, as reflected in her repeated use of ‘I’ when talking about how she dealt with the emotional abuse she got from her husband. This confidence appears to have helped her cope with the abuse, for example using laughter and answering her husband back. It is important to note that Salaphi’s reaction to her husband is beyond the socio-cultural expectations in the Swazi society. Women are said to be disrespectful if they answer back to their husbands. Women are expected to accept their husbands’ comments without response or question. Salaphi’s statement below reveals that she accepts herself, feels confident about who she is, and has a positive self image;

*“I use to be upset in the past, now I laugh about it, and I answer him back, even though he is serious most of the time. I know that mental illness can happen to anyone, and I feel well now that I am okay, I don’t care what he says, I can do everything now, I am not different from him, sometimes even better than him..... (she laughed) I take it lightly, laugh about it and tell him that I am free; he must not be concerned about me. I tell him the madness will get you, you are in the world, and anybody can become mentally unwell.” 5:131-134*

*“I am happy with what I do for now.” 9:245*

After being rejected by her boyfriend, because of living with the illness of the brain, Welile appeared optimistic that she will get the right man, because of her trust in God. Despite living with the illness of the brain, Welile hoped to restart her career as a pre-school teacher, using her certificate she had acquired a while ago;

*“I trust that God will give me my husband; it means that this one did not belong to me. I have separated with this one.” 6:164-165*

*“I have not started doing this yet, but I have a certificate of teaching in a preschool. This is what I want to do, and I think this could make me feel better.” 7:179-181*



Winile's desire was to disseminate the good news to other people living with the illness of the brain, that they can become better from the illness of the brain.

*"Recovery from this illness of the brain happens, others who have this illness I can encourage them that they can become better." 1:11*

While acknowledging some financial difficulties, Winile was also determined to generate money, to the extent of being willing to go to people's houses carrying and selling her vegetables. She used some of the left over vegetables to feed herself at home, a way of relieving her from the strain of looking for food.

*"I purchase a stock of oranges and bananas; then I go around selling around people's homes. This is very helpful to me that I sell and I do get money, and whatever remains I am able to eat, then I don't have to go and buy from the shops, I eat the left over stock." 5:126-129*

When she started her fruit business, Winile indicated that she did not have a good return, as some of her fruits were not sold. Yet, as she progressed with her story, she talks about how the demands for her products exceeded her supply. This accomplishment probably enhanced her recovery from the illness of the brain;

*I end up being stranded about what I will sell to them. They like the fruits that I sell. 7:182*

With so much enthusiasm and brightness in her face, Winile talked of her excellent financial, planning and time management skills

*"Oh! I do know how to manage my time very well (with excitement). You see, today since I attended my hospital review, I will then go back with a stock of fruits, then I will wash for the one who asked me to do it later on. I tell them when I will be free." 7:188-190*

Even though she was not accepted by one group in the community, Winile demonstrated resilience by finding one which did accepted her. In Swaziland it is common that, at the beginning of each year (January), a number of women form social groups where they save

money (for example £5 monthly) for Christmas shopping. At the end of the year the money is used to buy non-perishable food items which are then equally distributed amongst the members of the group. Most people end up having a lot of food for their families, which they use for up to six months after Christmas. So Winile joined one of these groups, and appears to be content to have made this decision;

*“Yes I do have children; it is very costly to raise them up.....But I joined a community organization. I am very happy during Christmas time..... I am able to feed them. At the end of the year we get a lot of food items, rice, meali meal and a lot of food stuff that I use to cook.” 7:194-197*

After accepting her admission to hospital, Tholu vowed to herself, that she would work hard so that she could quickly recover and return to the community. Repeated use of ‘*I told myself*’, seems to indicate an intrinsic motivation to get better and be discharged from hospital. I have written the ‘I’ in bold to demonstrate this repetition;

*“**I** told myself that now that **I** am here, **I** want to become better and come out of this place. **I** told myself that **I** must participate in all the set activities so that **I** can become better. **I** accepted every situation and told myself that **I** must participate in all the hospital activities.”33:694-697*

When she was admitted to hospital, Eli mentioned that she helped other patients, especially the elderly, with attending to their personal needs, such as plaiting their hair. After discharge from hospital she still wanted to pursue her passion. She registered to be trained as a rural health motivator. This is a volunteer who supports unwell people in the community, referring them to relevant health organisations for further management. A rural health motivator is more like a community support worker in the UK. Eli said;

*“I am looking forward to being trained as a rural health motivator in my area.” 18:368*

Similar to Winile, Selina explained that she would plan to start her fruit business gradually, with a few fruits, then expand as she makes a profit;

*"I want to start selling vegetables next to my homestead. I can sell apples, bananas, tomatoes." 12:237-239*

Even though Selina thought about following up of her former boyfriend's issue of not supporting their child, she quickly talked about her new plan of selling fruits. This she believed would promote her stable mental state;

*"I want to start my vegetable and fruits business and also go back to the social welfare services to report the father of my child for not giving money as he had promised. Focusing on my business will be of great help to me because I will not think about how this man refuses to support my child. Starting my fruit business will also help me to get fruits and vegetables; I will not go hungry then." 13:261-269*

Felaphi indicated;

*"I have benefited by reading and listening to information about forgiveness. I have tried to forgive these people.....It is not easy to forgive somebody who hurt you." 21:441,450*

To overcome her problems, Thobile uses positive self talk;

*"I want to work rather than sitting idly as I am doing at the moment." 5:87*

*"I want to start small by purchasing a few vegetable and fruits..... I know I will make it if I do baby steps. I am so positive that I will easily get a place to sell my fruits and vegetables. I want to start gradually selling fruits, I want to be active and make money before going back to my job." 5:95-97*

*"At times I would overpower the bad voice and listen to the good one who would tell me to eat, on his return, the bad voice would find that I have eaten the food, he would then shout at me and accuse me of eating poisoned food. But by that time I would be satisfied and happy, I would have suppressed this horrible voice that does not like me." 8:161-163*

Tenele was optimistic about her future plans, and this brought a sense of hope for the future;

*"I want to start school next year, and would like to be a police officer." 25:531*

Jojo is the only participant who expressed feelings of hopelessness due to being overwhelmed by financial challenges. Unlike most of the participants above, who would mention a problem

then talk about their plan of dealing with it, Jojo constantly talked about her financial struggles, and pondered over where she was going to get money. She did not mention any solution or intended plan of dealing with the problem;

*“I wonder where I will get money to come to hospital on my next visit, because a lot of people took my chickens on loan, they have not paid. I will be worried now how I will get the money from them.” 2:38-39*

#### **5.4.4.7 Being Assertive**

When faced with challenging situations, some participants were confident and expressed what they believed in, and what they wanted. Pholile told the story of how she confronted a lady in her neighbourhood, who persistently humiliated her;

*“She never stopped, she provoked me and provoked me. One day I answered back, I was going to fetch water.” 6:159-163*

Salaphi refused to be silent when forced to go to hospital, she stood up for herself. Also, instead of keeping quiet and letting her husband ridicule her, Salaphi stood up for what she believed in, going against the cultural expectations and norms, she answered her husband back, informing him about how she felt. In addition, she openly shared her mental state with her employer, possibly indicating that she accepted her condition, and wanted to teach others about her experience;

*“Oh yes, I told her about it, I did not want her to be surprised when she discovers. I did not hide it from her” 7:180*

*“.....they offended me, I was not supposed to keep quiet and let them do as they please to me.....What I did was to swear at these people forcing me to take something I did not want; they should not have forced me to take their medicine.” 4:88-98*

More than half of the participants appear to have been content about the decisions they made regarding certain issues, they assertively conveyed this to others and this seems to promote their feelings of self worth, and gave them energy to accomplish even more.

#### **5.4.4.8 Productivity and contentment**

A number of participants explained that they received satisfaction from being productive and committed to various activities, including house work, helping others and/or working in the community. Their ability to work was seen to promote recovery from the illness of the brain, as it appeared to serve as a therapeutic exercise. Salaphi stated;

*“I helped with house chores; hence I had recovered.” 2:52*

Salaphi encouraged her daughter to be accepting of illness of the brain, to live above societal stigma, and be optimistic. Even though talking to her daughter, Salaphi appears to be reassuring herself that mental illness does not stop productivity and becoming a professional, and living with the illness of the brain does not stop you accomplishing your desires;

*“We give each other advice, talk about the mental illness. I tell her to be free, that as long as I live she must be free and have no stress. I tell her that we are not the first to drink tablets, there are many people who drink tablets, I tell her that there are drivers who drive cars who drink tablets because they are mentally sick, nurses are sick, teachers are sick, doctors are sick, we all have this illness, so I tell her not to worry.” 6:158-160*

*“Working makes your heart to be happy... to have little money, rather than depending on others.” 7:173-177*

Welile said that she was happy about her decision to separate from her abusive boyfriend. Her focus was on implementing her plan of opening a pre-school;

*“I don’t want him anymore, especially because he drinks alcohol, I don’t want a husband who will be coming home drunk. He will be finishing all the money in drinking.” 6:164-167*

*“I have been trying to find ways of how I can start my own preschool. I want to start with a few children at a time, then I will expand as I get more money.” 7:179-181*

Winile said she wanted a more flexible, but regular work schedule, not necessarily to be employed;

*“I do work there now, but I want it to be on a regular basis. It is good that I am able to sell my fruits, and also do people’s laundry, and I am also free to attend my hospital appointments to collect my medication.” 9:258-260*

*“If I could do the laundry on Mondays, Wednesdays, and Fridays, then I could sell my fruits on the other days. Hayi!!! I could be very happy indeed.” 10:263,264*

Winile’s desire was to be involved in cooking for orphans, because she believes this will bring her happiness. It is possible that she is unable to be involved due to community stigma, and she perhaps rationalises this by commenting that the work she does keeps her busy and therefore she has no time to pursue her desire;

*“Being part of a community can make one feel better in the mind. I think that helping in the community kitchens where they cook for orphans, when you see the children being helped makes you feel happy. I would really like to be part of the community kitchens. But most of the time people ask me to wash their clothes and I make money, and as a result, I don’t have time to be involved with any other activity like the community kitchen.” 6:166,169*

Tholu showed a lot of enthusiasm and confidence as she talked about her means of generating income. According to Tholu being productive enhances independence, helps maintain a healthy relationship with the family, and supports her children;

*“I sell fruits and vegetables, I have avocado trees in my yard, when these are ready I sell them around and make good money. I manage my finances very well, including my money for pension and I give money to my daughters in law at times when they need money, sometimes I give out R200 (about £20) and I keep the R400 (about £40). I buy polony (this is a bread paste made out of pork) and cheese and I eat well. I don’t have to ask from my children to give me money. I just have fun with my children and by daughters in law.” 33:699-705*

In her extract below, Eli demonstrates her open-mindedness, looks for opportunities and is willing to learn new things. Excitement could be sensed when she was talking about her plans;

*“I am looking forward to being trained as a rural health motivator in my area. The community is going to train us this coming month. I am also a member of the Red Cross society, I subscribe E20 (£10) a month. I am looking forward to this new post, I have always liked working in the hospital, I like taking care of the sick people, I also have the skills and the passion of doing this job.” 18:372-374*

Thobile felt rewarded and satisfied about her past accomplishment, raising nine children, who were now happily married. Despite having been through difficult times with the illness, then divorce, she seems to choose to focus on good things, as these bring satisfaction and feelings of being valued;

*“this is true to me you know. I feel very great that I have been able to raise my nine children on my own. My children are all married and happy. This makes me feel great.”*  
10:194-196

Tenele was pleased about her hard work, making sleeping mats, which she sells at home and in South Africa;

*“I make and sell sleeping mats, about five per day. I then sell some of them in the country and some I ship to Johannesburg for better sales. I like making mats and feel good about making them”.* 25:518-520

*“At home I do some chores; I work and assist my mother.”* 27:561

*“I want to do more things that will promote my recovery, as we have already discussed.”*  
27:563

Being preoccupied with work helps Lulu to feel better;

*“I keep myself busy and work.....I clean the house and take care of my sister’s child.”*  
37:782-784

*“These activities benefits me because it make me to be surrounded by people, and this makes me forget about my illness.”* 38:816-818

#### **5.4.4.9 Being wanted, being valued**

The data suggests restoration of social networks has a positive impact on the recovery from the illness of the brain. The participants felt that their contributions to the lives of others added value to the community, at the same time being able to contribute made them feel fulfilled, valued and needed by society.

Tholu talked about how she developed a sense of responsibility, accountability and confidence for safe guarding the welfare of the children;

*“I am involved in a community project that helps to feed the orphans. I have been chosen to be in charge of the women who cook in the community kitchen for these children, and my responsibility is to make sure that the orphans are well fed....that all the food is given to the children..... The food must not be taken by the people who prepare it. I feel very happy about being part of this project.” 34:720-725*

Felaphi, like Tholu took delight in being with children and supporting them. Perhaps being with children serves as a place of comfort, as, unlike adults, they are unlikely to ridicule them or label them as mentally unwell. Felaphi proudly stated;

*“At church I teach Sabbath School to children. Children are not a problem, and I enjoy doing this.” 23:438*

Salaphi decided to find something good out of her experience of living with the illness of the brain. Being the first one to live with mental illness in her family, Salaphi strengthen and supported her daughter who was also diagnosed with mental illness. She confidently said;

*“So I have to be strong for my daughter, she has recovered now, she is normal, we talk and chat about this mental illness. I feel I give her excellent support.” 6:146-152*

In her quotation below, Salaphi seems to believe that her short stay in hospital was enhanced by her zealous attitude to work and commitment to being productive

*“When admitted in hospital I did not stay in hospital for a long time..... I worked hard, I washed the dishes after meals, and I cleaned the rooms where we slept, I put polish. I respected the nurses, even those who were younger than me.” 11:300-302*

After starting her business, Winile could not cope with the demands for her products. Even though she said she was disappointed that she was not getting more money because of being out of stock, it is possible that she perceived her service as essential to the community, hence she was motivated to get a larger stock;



*“People buy a lot, the fruits are on demand, I end up being stranded about what I will sell to them. They like the fruits that I sell. ” 7:182;*

Felaphi valued peace amongst members of the community, and expressed how, by using Christian principles, she wanted to be an example in promoting peace and harmony amongst members of society;

*“.....the church is meant to be place of peace, joy and harmony. I feel that I should forgive others.....” 22:453-456*

Nono appeared fulfilled by participating in church activities; cleaning the church.

*“I attend church there; I clean the church.....”3:51*

Lulu seems to indicate that, even though she was not involved in community projects, these promoted recovery from the illness of the brain; hence she planned to participate, specifically in working with children. Lulu’s use of the word ‘capable’ indicated her confidence in doing this activity. She stated;

*“I.....would like to participate in the community orphan feeding program in my area. I feel I able capable of taking care of children.” 37:788, 789*

## **5.5 Conclusion**

This study has revealed four distinctive super-ordinate themes regarding the perceptions and experiences of living with “*sifo sengcondvo*” transliterated as the *illness of the brain* [schizophrenia], and their meaning of recovery from it. Participants talked about things which enhance and those that hinder their recovery from this illness.

The first super-ordinate theme: Emotionality of the illness of the brain, revealed that the name given to the illness participants were diagnosed with, “*sifo sengcondvo*” is different from the one ascribed to them by professionals. Maybe this is the reason for what seems to be a conflict between participants’ description of recovery and how they perceive recovery could be enhanced by those deemed to support them. Within this super-ordinate theme, participants also describe their experiences of the illness of the brain, deliberating on how the illness changed them, and how these changes possibly affected their emotions and those around them, to such an extent that living with the illness and others is perceived as ‘painful.’

The second super-ordinate theme: Pain! Living with the illness and with others, is centred on being misunderstood by those around them. This was perceived by Swazi women as a hindrance to their recovery from the illness of the brain. Participants believe that, at times, others (hospital staff, family and community members) are paternalistic, judgmental and sometimes use coercion in an attempt to support their recovery. Consequently, the participants are labelled with names they do not like, and the use of such names make them feel humiliated and shameful. Within this super-ordinate theme participants seem desperate to be heard. Even though they tried to talk, they felt that people do not want to listen to them, but would rather listen to those accompanying them.

In the third super-ordinate theme, ‘Luhlanya lolu, ungalunaki’ transliterated as: ‘she is mad, just ignore her,’ the humiliation created by the labels continues. One of the things which come with the pain of living with the illness of the brain is the stigma the Swazi women experienced; from hospital staff, their families and the community. Participants talked about how they were excluded from certain groups, because of the illness. A number of participants felt that the

decisions for being taken to seclusion were not justified measures to promote their recovery. Moreover, the seclusion environment was reported to be uninhabitable; compromising recovery and causing a lot of discomfort and distress. Other examples of stigma and/or discrimination were noted at the work place. While some of them felt ready to resume work, their employees felt they were not ready. This created further frustration because of a scarcity of income. While some participants strived to overcome this by setting up their own business, this strategy often took time to come to fruition. It is likely that because of discouragement and low-self esteem, the Swazi women in this study felt they could not achieve anything beyond what they have, and as such their description of recovery is in terms of ‘going back to normal.’

Participants’ last super-ordinate theme brings to light the unique needs of things they feel promote their recovery form ‘*sifo sengcondvo*.’ Their families and significant others played an important; by providing emotional and financial support. Participants also verbalised that they felt better when accepted by various family members and communities. Doing various chores and domestic duties was perceived as rewarding, often leading to participants feeling included, needed and valued through being able to contribute to community groups. Some health professionals were acknowledged for the contributions they made to their recovery when they were admitted to the hospital. Recovery enhancing activities by staff included: spending time with them, talking with them, encouraging them to be involved in hospital activities such as doing laundry, encouraging family visits, giving medication on time, and being given leave to their community. These findings add to the limited body of knowledge of how recovery from an African perspective can be enhanced within communities, families and health settings. Further discussion of these finding and how they relate to previous research studies, as enumerated in chapter 2, follows in the next chapter.

# Chapter 6

## Discussion

### 6.1 Introduction

This study has disclosed unique understanding and insight into the lived world of women living with the illness of the brain (schizophrenia) in Swaziland, and the meanings they attribute to recovery from it. The findings could be used to inform and improve practice within mental health care in Swaziland, and to facilitate assimilation of other social networks that have been identified by the participants as essential to their recovery journey. In Education, curricula could be designed to equip health professional, such as nurses, with knowledge and skills suitable to patients' needs and supporting them through their process of recovery. Mental health policies could be developed to reflect the voices for whom they are designed, and further research could be conducted in related areas. It is hope that the finding of this study will promote patient-focused clinical practises, geared to empower SUs and promote recovery of people living with the illness of the brain.

Following a detailed analysis of participants' stories in chapter 5, four super-ordinate themes have been identified. The inclusion of direct quotes from participants' stories does not only give them a voice, but it also provides the reader with clear evidence how the sub-ordinate and super-ordinate themes were developed (Smith, et al., 2009). Three of the super-ordinate themes: The emotionality of the illness of the brain; Pain! Living with the illness and with others; and *Luhlanya lolu, ungalunaki*: She is mad, just ignore her; bring a fresh insight into the experiences of Swazi women living with schizophrenia, highlighting what hinders their recovery in the community, within the family and/or at the SNPH. The last super-ordinate theme "Kubancono" transliterated as 'Being better' also adds knowledge regarding Swazi women's perceptions of

what hinders and promotes their recovery. This super-ordinate theme is discussed within the last two sessions of this chapter.

In order to illustrate how the analysed data answered the research questions, the findings will be discussed according to each of the sub-ordinate and the four super-ordinate themes; within the context of the family, community and the hospital. Participants' description of the enhancers and hindrances of their recovery from the illness of the brain within the family and community context are intertwined, as discussing them in separate categories could lead to unnecessary repetition. The discussion is divided into three main sections: Swazi women's experiences of living with illness of the brain; Swazi women's perceptions of the process of recovery from illness of the brain, Swazi women's perceptions of what enhances and hinders their recovery process.

## **6.2 Research Questions**

- ❖ What are the experiences and perception of living with schizophrenia from Swazi women living with this illness?
- ❖ What are the perceptions and experiences of recovery from schizophrenia of Swazi women diagnosed with this mental illness?
- ❖ What promotes and/or hinders their recovery at: the SNPH, home and community?

Below, Table 6 shows a summary of the how the findings within the super-ordinate and subordinate themes answered the research questions.

**Table 6** *Research questions and themes*

<b>The Research Questions</b>	<b>Findings: Super-ordinate &amp; Sub-ordinate themes</b>
What are the <b>perceptions</b> and <b>experiences</b> of Swazi women living with schizophrenia? <b>Hindrances</b> of their recovery, at <b>home and the community, and at the hospital?</b>	<p><b>1. The emotionality of the illness of the brain</b> (The illness defined, Changed self and feelings of rejection and desperation, Tension &amp; stress of the illness)</p> <p><b>2. Pain! Living with the illness and with others</b> (Family &amp; community, hurt by staff)</p> <p><b>3. Luhlanga lolu, ungalunaki: She is mad, just ignore her</b> (Rejected by Family &amp; segregated by society: tarnished; Discrimination at work/employment; by professionals; <b>Seclusion</b>)</p>
What are their <b>perceptions</b> of recovery from schizophrenia?	<b>4. Kubancono: Being better:</b> It's up to me, motivation to overcome
What are their <b>experiences</b> of recovery from schizophrenia: <b>Enhancers</b> of recovery, at <b>the hospital, community and home</b>	<b>4. Kubancono: Being better</b> (Family & community, hospital, Religion, Medication, Assertive, Productivity & contentment, being valued)

### **6.3 Swazi women's perceptions of the illness**

The definition of mental illness from previous studies is associated with loss of self, loss of identity and being lost from the community (Bradshaw et al., 2006; Wisdom et al., 2008), a description to some extent given by participants in this study. However, the women in this study also indicated cultural influences that contributed to them becoming unwell. I will first discuss findings about their perceptions and experiences of living with illness of the brain.

#### **6.3.1 Schizophrenia: 'their' definition**

As already pointed out in previous chapters, language became a critical issue in this study. Even though the aim was to explore the perceptions and experiences of Swazi women living with a medical diagnosis of schizophrenia, the participants did not refer to their condition as it was

stated on their health records. Instead, they perceived themselves as living “*sifo sengcondvo*” transliterated as ‘illness of the brain’, with none talking about the experience of living with schizophrenia. The disparity between the naming of the illness on the part of the participants and that of the staff at SNPH could be due to a number of reasons. In the siSwati language, the word ‘schizophrenia’ does not exist, and what is recorded in the patient notes is a medical diagnosis, that it would appear, is not shared with the patient. This is similar in the Chinese socio-cultural context. Ng et al., (2012) stated; “*There is not a distinct mental disorder called schizophrenia according to traditional Chinese medicine, and mental illness is broadly divided in to two categories, namely, “Kuang” – psychosis with excitation and “dian” – psychosis without excitation or epilepsy.*” (p.1)

One issue in naming schizophrenia as the ‘illness of the brain’ is that it is not specific. Illness of the brain could be understood as anything from organic illness, for example, epilepsy, brain tumour, to non-organic disorders, such as schizophrenia, depression. Recovery from non-specified illness could possibly be hindered by inappropriate interventions and treatment. One of the purposes for publishing the DSM 5 was to synchronise diagnoses of mental illnesses in order that clinicians can share a point of reference, which would in turn influence the type of treatments offered to those deemed to be living with such illnesses (Watts, 2012). Nevertheless, since its publication there has been debate around diagnoses of psychiatric conditions. The argument being that, if used in formulating diagnosis it will over ‘medicalise’ people presenting with what could be considered as ‘normal’ behaviour. For example, in previous DSMs depression was ruled out if a patient presented low in mood following bereavement. Yet, the inclusion of bereavement in the DSM 5 will mean that a person could be diagnosed as having depression while going through the normal grieving process. Rather than making things easier and quicker in managing mental illness, there is speculation that the DSM 5 could lead to further medicalisation of everyday problems (Watts, 2012).

In reference to this study, in her story, Salaphi talked of dancing in the house at her in-laws.

While this is out of keeping with cultural norms of politeness, it does not equate to mental illness. It is interesting to note that similar findings were revealed in a study undertaken in the UK, where women from the BME confirmed that they experienced stigmatisation from their in-laws, who were critical of them and related some of their behaviours to mental illness (NHS, Health Scotland, 2008).

Swazi women living with the illness of the brain are not informed, by hospital staff, that they have a diagnosis of schizophrenia. It is likely that informing them about their diagnosis could serve as a catalyst in their recovery journey (Penn & Nowlin-Drummond, 2001; Mezey et al., 2010). Mezey et al., (2010) conducted a study on perceptions, experiences and meaning of recovery in patients living with severe mental illness with forensic history. Most patients expressed the importance of knowing both their diagnosis and their medication; stating that this helped them to understand their mental state and in controlling and dealing with triggers of the illness. Lack of knowledge was associated with '*walking in the dark.*', a notion that could be applied to the women in this study. Similarly, studies undertaken by Tooth et al. (2003) and Ng et al., (2008) revealed that patients and relatives who are informed about the mental illness and medication are more likely to be compliant with their care, and they receive good support from their significant others.

However, the doctors' decision not to reveal the diagnosis could be interpreted as being paternalistic, hindering a person's right to be independent and make informed decisions within the context of their own life. Paternalism, in this instance, is based on professionals' perspective, rather than giving recognition to how the patient is able to make sense of the illness, perhaps



being detrimental to the recovery process (Ono et al., 1999). Previous studies have confirmed that paternalistic attitudes towards patients can hinder their recovery from mental illness (Mancini et al., 2005; Bradshaw et al., 2006; Ng et al., 2012). In keeping the women '*walking in the dark*' in terms of their diagnosis, it could be argued staff at the SNPH were disadvantaging them with regard to regaining a sense of identity, knowing and accepting who they are.

However, a study carried out in Japan (Ono et al., 1999) found that 50% of psychiatrists informed patients about their diagnoses of schizophrenia, while 37% only informed patients' relatives. The latter were concerned about the stigma often attached to the label schizophrenia, believing that non-disclosure of their diagnosis was a way of protecting them. As already discussed in the first chapter, in the past the use of the term schizophrenia has been linked to feelings of hopelessness, despair and despondency (Andreasen, 1999; McLynn, 1996; Toner, 2000; Rice, 2006; Knapp et al., 2009; Snowden, 2009). Again, this is paternalistic, but some would suggest that in knowing the challenges people have to face will promote the development of coping strategies that within the context of the illness will lead to a better quality of life (Penn & Nowlin-Drummond, 2001; Tooth et al., 2003; Ng et al., 2008; Mezey et al., 2010).

There is evidence to support that being labelled with the diagnosis of schizophrenia can have a negative impact on one's recovery (Rosenhan, 1973). In light of this it could be considered that Swazi women's definition of schizophrenia as an 'illness of the brain' is beneficial in that the stigma associated with the label of schizophrenia is avoided. Labelling theory suggests that once given a label of a mental illness, it is difficult to discard and attract response from others that are in keeping with the label rather than the person (Rosenhan, 1973). Likewise, those labelled may behave in such a way as to meet the expectations of the label (Dinos et al., 2004).

Leete's story brings to light the common challenge of being labelled with schizophrenia;

*"I can talk, but I may not be heard. I can make suggestions, but they may not be taken seriously. I can report my thoughts, but they may be seen as delusions. I can recite experiences, but they may be interpreted as fantasies. To be a patient or even ex-client is to be discounted. Your label is a reality that never leaves you; it gradually shapes an identity that is hard to shed"* (Leete, 1989, p. 199).

Swazi women in this study have revealed a new insight in their perception of being diagnosed with mental illness. The differences in the label given, 'illness of the brain' by those living with it and schizophrenia by the staff at the SNPH, appears to be in-line with the conflict between the medical model and that of recovery. The frame of reference in which an illness is seen to influence how staff perceive their role in relation to providing care; and patients' perceptions of how they want to be treated by staff. In other words, it appears that patients want to be involved in their care and treatment so that their individual needs are addressed; and that they are more compliant .

However, medical influence, (diagnosis) affect the way in which clinical staff interact and support patients living with mental illness, in this case schizophrenia. The inclination is to treat symptoms with medication, rather than focus on patients' individual needs. Indeed, similar to the findings of (Mezey et al., 2010), the women in this study had a desire to take the lead in managing their illness, as well as their medication and to ultimately remain in control of their lives.

### **6.3.2 Culture and defining the cause of the illness**

The outcomes of this study disclosed that cultural beliefs and values have an influence on the women's perceptions of the illness of the brain and how they are perceived by others. These must be known and taken into consideration when supporting or caring for people living mental

illness (Calabrese & Corrigan, 2005; Myers, 2010; Lam, et al., 2011; Ng et al., 2012). In this study, for example, Pholile believes that the illness started after she was given a hand shake by a stranger; and Eli said that the illness started because her books were used for witch craft, by one of her peers, whom she believes stole them for that purpose. From my knowledge and experience as a native Swazi, there is a general belief within this society that people with bad motives can cause harm to others by spreading poisonous, harmful substances to those they chose to target. These toxic substances could be spread through hand shaking and/or smearing it on the target's belonging(s); for example a book. Therefore, consideration of their cultural values and beliefs must be an integral part of professional intervention, if services are to be beneficial to people living with the mental illness. In previous studies (Jenkins & Carpenter-Song, 2005; Mancini et al., 2005; NHS Health Scotland., 2008; Ng et al., 2008; Kalathil et al., 2011; Lam et al., 2011; Ng et al., 2012) some people did not benefit from health services because of either cultural conflicts or exclusion of their cultural values in their plan of care.

The findings above echo a report by Lambo (1955), on how cultural factors affected patients presenting with paranoid psychosis amongst the Yoruba tribe, in Nigeria. He stated that culture does not only have an influence on how people define their experience of mental illness, but it also has a significant impact on the clinical presentation. For this reason, a culturally structured model of care is paramount in supporting and promoting patients' recovery from mental illness (Kulhara & Chakrabarti, 2001).

Understanding patients' cultural values promotes empathic care and understanding, as opposed to being judgemental and critical. For example, rather than being judgmental, and treating patients as 'paranoid', staff who take time collecting subjective information to clarify issues that brought them into services, are more likely to identify key issues around the mental illness,

leading to early intervention and promotion of recovery (Kulhara & Chakrabarti, 2001; Torgalsboen & Rund, 2002; Calabrese & Corrigan, 2005). Following a study, carried out in Edinburgh, with BME women living with mental illness, many of them indicated that they felt staff needed to know more about their cultural values in order to better support their recovery, noting that their recovery was hindered by staff's lack of insight into their culture (NHS Health Scotland., 2008). Likewise, Ng et al (2012) revealed that recovery from mental distress was enhanced by professionals who integrated patients' use of their cultural traditions in dealing with hearing voices. For the women in this study acknowledging their cultural beliefs on the part of staff may have reduced their level of distress in trying to tell, but not having their story heard.

#### **6.4 Impediments to recovery from the illness of the brain**

Below is a discussion on Swazi women's views about various issues they believed hindered their recovery from the illness of the brain; within the context of the hospital, home and the community. Such issues included treatment received at the hospital, their unpleasant experience of seclusion, and staff's attitude during their hospital admission.

##### **6.4.1 At the hospital**

This study brought insight into the lack of, or minimal involvement of patients when prescribing and administering medication, perhaps leading to over sedation. A few participants believed they were chemically restrained, and this resulted in them experiencing severe side effects. After she was involuntary brought to hospital Pholile said she was given an injection. Despite her repeated attempts to explain to the nurse and the doctor that she did not need the injection, she was told to keep quiet. These findings echo those of previous studies (Pejlert et al., 1999; Tooth et al., 2003; Mancini et al, 2005; Kalathil et al., 2011) whereby people living with mental illness indicated that coercive treatment from professionals hindered recovery by instilling feelings of fear and vulnerability.

Findings from this study indicate that hospital staff were unable to listen to service users. There appeared to be an assumption that those living with illness of the brain cannot accurately recall their experiences, and therefore lack the ability to truthfully relate this to others. Perhaps, they are viewed by staff and others as having an illness that precludes them from talking sensibly. Similar findings were revealed in a study undertaken by Mancini et al (2005). In this study the women made statements such as; “*they think I am mad all the time.*” Pholile talked about how she was ignored by staff at the psychiatric hospital, and told to keep quiet, as she tried to explain to the doctor that she was well. It is possible that the doctor thought she was not aware of her behaviour, and therefore could not offer any relevant information regarding her mental state.

There is no indication that patients are given information about their prescribed medication, and its side effects, the hospital. Pholile talked about how the injection “*dragged*” her down, emphasising how she did not need it, and ended up having side effects, and experiencing over sedation, which subsequently delayed her recovery. Pholile talked of how she “*lost control of everything.*” These findings are in keeping with other studies (Chernomas et al., 2000; Jenkins et al., 2005; Mancini et al, 2005 Bradshaw et al., 2006; Ng et al., 2008), where participants reported that their recovery was hindered by the side effects of medication, commonalities being drowsiness and fatigue. Participants in those studies reported having no energy and motivation to work on their daily chores. Some participants felt that doctors had no time to talk to them about the medication they prescribed, their side effects, and/or to consider alternative treatment (Jenkins et al., 2005).

#### **6.4.1.1 Seclusion**

Seclusion is one of the sub-ordinate themes. I have chosen to specifically discuss this theme independently because of the outstanding new knowledge that has emanated from this study. While seclusion was not within the scope of this study, all participants who talked about their experience in seclusion discussed it in terms of hindering their recovery. Seclusion, as either a

hindrance or enhancer of recovery has not been revealed in any of the studies reviewed in chapter 2, but Swazi women disclosed that their experience of seclusion hindered their recovery from the illness of the brain.

Seclusion is intended to be a place of safety, where patients are cared for in isolation due to a risk of harm to self or others. In the UK emphasis is placed on using seclusion as a last resort; with other strategies, such as 1:1 sessions, time out, deemed to be those to be utilized before reverting to seclusion. In addition, service users placed in seclusion should be clearly informed of the reason for such an act, and about their rights (Knox & Holloman, 2012).

There are differing views about the use of seclusion in promoting recovery of people who are mentally unwell. Although some people acknowledged their mental state improved following seclusion, others believed that using other forms of interventions could yield better outcomes (Menninger, 2001; Saks, 2002; van der Merwe et al., 2009; Knox & Holloman, 2012). In contrast to the negative effects of seclusion, van der Merwe, et al (2009) found that the use of seclusion can be significant in promoting recovery, if the environment is conducive. In their review of the literature on seclusion, they found that a well decorated seclusion room, with the right temperature and furniture, positively affected the emotions of those in seclusion, as it provided a calming effect, thereby improving their mental state and subsequent recovery (der Merwe, et al., 2009).

However, findings from this study indicated the women were not involved in making the decision to go into seclusion, and as such they seem to express feelings of anger and disappointment. In seclusion, participants felt hopeless, isolated, lonely, and did not benefit from the experience, but instead felt they were being punished by staff. Such findings are in keeping with those reporting on the experience of seclusion in western society (Saks, 2002; van

der Merwe et al., 2009; CQC report, 2012). Findings from this study also revealed concerning information about the rationale behind the prescription of seclusion. At times, it appeared that service users were inappropriately sent to seclusion. For example, one participant was sent to seclusion by a nurse after she was reported, by a fellow patient, for not being able to sleep during the night.

Most participants reported that being in seclusion gave rise to feelings of distress, likening the experience to torture and imprisonment. It is likely that lack of staff guidelines and policies on the use of seclusion resulted in this unpleasant experience. Evidence suggests that some staffs' use of seclusion is possibly due to; fear of harm from patients, lack of knowledge and skills in managing conflict and/or challenging behaviour, or a way of regaining control of the situation (Care Quality Commission, 2014). Findings in this study reveal that the seclusion environment hindered patients' recovery: no water to drink (one of them drank from the toilet), no bed and bedding, they slept on a concrete floor. It has been suggested that a clear conducive environment enhances recovery from mental illness by restoring a sense of being valued and treated with dignity and respect (Mezey et al., 2010), for the women in this study being put in seclusion only devalued them as human beings and disrespected their dignity.

#### ***6.4.1.2 'Who is in charge?'***

This study revealed that patients were physically and or emotionally abused by hospital. Perhaps staff's use of physical force, mortifying language and labelling them with names to describe some of their physical features when dealing with patients, was either an indication of being burnt out from work pressure, lack of knowledge about the negative impact of such language to the process of recovery, and/or a way of showing services users that they (staff) are in control (Oaks, 2012). The psychological effects of coercion have been noted to be detrimental to the recovery process, commonly leading to constant fear, discomfort, a low sense of self-worth,

and over dependency to staff (Mancini et al., 2005). Patient with a high self-esteem and sense of self were found to recover quicker than those with low self-esteem (Beck et al., 2012).

Within the SNPH there is no place for patients to report a complaint, even when they attempted to make one, they did not receive any feedback to indicate that appropriate actions were undertaken. Perhaps, making complaints gives services feedback from the SUs point of view, and acting upon them is very important in promoting quality of services. Most of participants' stories seem to indicate that paternalism hindered their recovery from the illness of the brain. Winile's repeated comments, "*I have told myself, indeed that my life in on the doctors' hands*" and "*..... stick to the doctor's rules*" indicates her loss of control within her life, reflecting her dependency on the doctor's instructions. While a number of participants acknowledged the benefits of taking medication, there have been instances where they (participants) seem to indicate that they were not autonomous in making the decisions about taking the medication. At the end of her interview, Pholile recommends that professionals should listen to them (patients), perhaps indicating her own lack of autonomy in the care she received.

Mancini et al., (2005), conducted a study on how patients recovered from serious psychotic disabilities. One of the barriers to their recovery was the power imposed on them (patients), by professionals; with a notion of protection or supporting the vulnerable being their mantra. Paternalism is a situation where professionals' make decisions or choices for patients without involving them, in an attempt to protect them, either emotional or physical stress. Professionals take a stance of making the decision(s) in the best interest of patients (Mancini et al., 2005). Within the SNPH paternalism was evident from the start of the women's illness trajectory, with diagnosis being withheld and decisions being made on their behalf without consultation.



There is likelihood that the medical model has an influence in clinical practice in Swaziland, so that there is more focus on the illness rather than the person. From the participants' narrations, some staff at the SNPH appears to have adopted critical, judgmental and indifferent attitudes. The language used depict staff as superior and in higher positions and as having more expertise than the participants, with similar findings emerging in other studies (Knight et al., 2003; Mancini et al., 2005). In each of these studies participants stated that they felt judged by those in position to help and that 'the system focused on the illness such that they felt invisible.' The use of coercion is linked to paternalism, so that care planning and patient support is professionally led rather than SU driven (Ridgway, 2001; Tooth et al., 2003; Mancini et al., 2005; Ng et al., 2012). Mancini et al (2005) emphasized that coercion has been found to be the primary cause of negative effects to the care of people living with mental illness, creating persistent feelings of fear and hindering a return to independence.

#### **6.4.2 At home and in the community**

Hindrances to recovery from the illness of the brain, within the family and community context are discussed under the following: the added burden, stigma, and strained relationships.

##### ***6.4.2.1 The added burden!***

Participants' stories of their revealed that living with the illness of the brain is **stressful**, and can hinder their recovery. This comes about as a result of a number of issues. Firstly, hearing voices and having distorted perceptions changed their behaviour and the way they interacted with others, at times resulting in them being a danger to self and/or others. Compliance with medication and high levels of support during such times, has been associated with a positive outcome of the recovery journey by service users and their significant others (Tooth et al., 2003, Ng et al., 2008; Mezey, et al., 2010). Perhaps, due to lack of knowledge and understanding of what they were going through, the women in this study felt that those around them either disengaged or forced them to make a change in behaviour to one considered socially acceptable. These reactions on the part of significant others led participants to experience feelings of

rejection, desperation, tension and stress (Kulhara & Chakrabarti, 2001; Myers, 2010; Manuel et al., 2012).

Secondly, having an inability to control their behaviour, as a result of the illness, resulted in participants experiencing a sense of loss and desperation. They were sensitive to such feelings of loss and could relate all the events associated with it. For example, Winile, after walking naked in the park, still had to live in her local area, raising the question of how receptive the community was of her when she returned home presenting as 'normal.' These examples demonstrate the basic assumptions of recovery from mental illness; recovering from the consequences of the illness can be much more difficult than recovering from the illness itself (Dinos et al., 2004). Those working with people through their recovery journey should be aware that being asymptomatic is not necessarily an indicator of one's recovery (Anthony, 1993; Kulhara & Chakrabarti, 2001; Myers 2010). In this study, for example, it is likely that, even though presenting with no symptoms of the illness, a person could still be recovering from internal stigma.

Thirdly, participants revealed that recovery was further hindered by the distress that came about as a result of financial constraints. One woman talked about how lack of money triggered feelings of anxiety, concerning where she and her family were going to get food. Similar findings emerged from Manuel's (2012) study, investigating the experience of women's transition from hospital to the community. Women in this study also said they preferred to stay in hospital than to be discharged home, because of fear that the public funds allocated to them would not be sufficient to pay their bills once discharged home. The difference between the findings in Manuel's study and the present one is that there are no public funds allocated to

people living with mental illness in Swaziland, and they also receive no support with accommodation.

#### **6.4.2.2 Stigma**

Findings from this study indicated that people living with the illness of the brain experienced stigma: at home, in the community and within the mental health setting. This is in keeping with findings from a number of previous studies (Chernomas et al., 2000; Smith, 2000; Ridgway, 2001; Spaniol et al., 2002; Knight et al., 2003; Tooth et al., 2003; Jenkins & Carpenter-Song, 2005; Bradshaw et al., 2007; NHS Health Scotland, 2008; Armour et al., 2009; Mezey, et al., 2010; Lam et al., 2011; Manuel et al., 2012; Ng et al., 2012; Bromley, et al., 2013). Sources of stigma are said to be from within the self (of one living with mental illness); from professionals (police, doctors, nurses) (Knight, et al., 2003; Jenkins, 2005); and from society and family members (Chernomas et al., 2000; NHS Health Scotland, 2008).

Stigma from all of these sources brings about challenges to social integration for people living with the illness of the brain. Furthermore, in a study carried out by Bromley et al., (2013) focusing on the community experience of individuals diagnosed with serious mental illness, showed that participants were mostly stigmatised by those closest to them (family and friends). Such stigma can imbue weakness and incompetence, giving rise to low self-esteem in those on the receiving end. Such negative beliefs about self often leads to separation from the community or society in order to avoid further humiliation (Corrigan & Watson, 2002). Because of the above, stigma can hinder independence, promote boredom and give rise to feelings of rejection and under achievement, all factors that could be considered the antithesis of recovery (Smith, 2000; Ridgway, 2001).

Salaphi, for instance, wanted to be herself and express her emotions through dancing, this was misinterpreted by family members as being unwell, because in the Swazi culture dancing at the

in-laws is not accepted, hence her being labelled as mad. Pholile was also confronted by stigma, by her family and community referring to her as '*a mad women.*' This was difficult to understand as Pholile was only engaging in activities, burning ripped clothes, considered as normal in Swazi society. Perhaps this is not just about stigma, but also demonstrates how people are treated according to a given label.

A survey conducted in a Nigerian university teaching hospital revealed that stigma and discrimination was widespread within a population deemed knowledgeable about mental illness. Participants were nurses, medical students, and other senior members of staff, and more than half believed that mental illness was caused by witchcraft, with the rest attributing mental illness to being possessed with evil spirits (Ukpong & Abasiubong, 2010). Again, such attitudes towards patients living with mental illness can lower their self-esteem and hinder the process of recovery (Bromley et al., 2013). In particular, stigma received from professionals increases the chances of service users not accessing services due to lack of confidence and trust (Lyons et al., 2009). This study has found that living with the illness of the brain poses agony and pain to those who experience it. This comes about as a result of confusion within the self, and the pain of not being accepted and understood by others (stigma). Stigma can pervade all aspects of a person's life compromising physical, psychological and emotional wellbeing. For the women in this study stigma was a challenge they faced on a daily basis and one they had to master if they were to progress on their path of recovery.

#### **6.4.2.3 Work discrimination**

Financial constraints and inability to meet daily needs (food) becomes problematic due to lack of employment amongst people living with mental illness (Chernomas et al., 2000; Smith, 2000; Ridgway, 2001; Spaniol et al., 2002; Knight et al., 2003; Tooth et al., 2003; Jenkins & Carpenter-Song, 2005; Bradshaw et al., 2007; NHS Health Scotland, 2008; Armour et al., 2009; Mezey, et al., 2010; Lam et al., 2011; Manuel et al., 2012; Ng et al., 2012; Bromley, et al., 2013). Within this study, it appears that some employers in Swaziland still have a negative

attitude towards people living with mental illness. Although Thobile felt that she was ready to return to work, her employer refused to accept her back, informing her that she was not yet ready to return. Although evidence suggests people living with mental illness are capable of sustaining their jobs, even though they could still be experiencing some of symptoms of mental illness (Albert et al., 2011). Employers need to be sensitized and educated about mental illness and how best to work with people who have had such experiences, as this could aid in reducing stigma and discrimination (Hoffmann & Kupper, 2002; Rethink report, 2003).

Positive action needs to be taken with regards to changing societal attitudes in Swaziland. For example, in Swaziland the Government could provide financial incentives to support employers in employing those who have recovered from illness of the brain e.g. tax relief or tax rebates. In Germany Angermeyer and Matschinger (2005) found that the attitude and interaction of the public towards people living with schizophrenia was positively changed after they (public) were given information and education. These findings also bring to the fore the urgent need to educate the general public on the illness of the brain and the recovery process, with the hope that this will start to make inroads in changing society's beliefs and attitudes in Swaziland.

#### ***6.4.2.4 Relationships on edge***

While interacting/socializing with friends and peers is significant for mental well-being, the women in this study reported isolation, loss of self and loss of identity because of living with illness of the brain. This is a common experience that leads to further alienation, and subsequently hindering recovery by exacerbating feelings of low mood (Chernomas, 2000; Repper & Perkins, 2008; Wisdom et al., 2008; Lysaker et al., 2010; Mezey, 2010). Findings in this study revealed that, in particular, close relationships are strained when living with the illness of the brain; a similar trend that emanated in the NHS Health Scotland, (2008) study where the participants reported that they were ridiculed by their in-laws.

In developing countries, families and significant others of people living with mental illness often take a lead role in supporting them throughout their recovery journey (Thara et al., 2007). In their study in Chennai, India, Thara et al. (2007) found that families taking on such responsibility often felt it to be a strain and became distressed. As evident in this study families of Swazi women living with illness of the brain often have negative attitudes towards them; for example, referring to them as ‘mad women’. When considering Thara et al.’s (2007) findings it could be suggested that the attitude of the family might have been triggered by the stress and strain associated with caring for someone who is mentally unwell.

The clinical importance of these findings indicates the need for compassionate support for patients and their significant others. This would require professionals to be mindful, not only of the tasks inherent in caring for service users, for example administering medication, but to work together with patients and significant others to ascertain the level of emotional support needed in order to address the psychological aspect of both parties’ experience. In short, the strategies for health services aimed at promoting recovery must look towards working with patients and their significant others in restoring their mental wellbeing in order that the former can regain a sense of self and the latter can support them in doing this (Pitt et al., 2007; Wisdom et al., 2008; Romano et al., 2010; Mezey, 2010; Wood et al., 2013).

### **6.5 Perceptions of Recovery “Kubancono: Being better”**

Swazi women living with the illness of the brain identified five dimensional aspects to their process of recovery. These encompassed; recovery being self-defined; triggers and/or symptoms are absent or minimised; motivation to engage is enhanced; dignity and self-respect are established; and there is ability to sustainment of healthy interpersonal relationships.

### 6.5.1 Recovery defined

The unique explanation of recovery from the illness of the brain by each participant in this study concurs with most consumers' description of recovery; as an idiosyncratic (individualised), unique, dynamic process that can only be subjectively defined by those who experience it (Houghton, 1982; Deegan, 1988; Leete, 1989; Unzicker, 1989; McDermott, 1990; Meddings & Perkins, 2002; Tooth et al., 2003; Jenkins, 2005; Noiseux & Ricard, 2006; Pitt et al., 2007; Mezey, 2010; Lam et al., 2011; Thara, 2012; Wood et al., 2013). As a process, Swazi women acknowledged that they were not fully recovered; even during the time of the interviews some participants expressed a desire to continue to '*get better*'. Thobile's perception of recovery as a process brought an understanding to the fact she was happy to recover slowly, because she '*gained more and more strength*' to perform other duties as she progressively became better. The findings in this study reveal a strong notion that recovery is subjectively defined. The Swazi women emphasized that, because of their experience in living with the illness of the brain, they qualify to tell others about their 'life world', and how they could best support others to become better. Again, this has been a common finding from other studies conducted with women and men living with serious mental illness (Chernomas, 2000; Ridgway, 2001; Tooth et al., 2003; Lam et al., 2011; Patterson et al., 2011; Roe et al., 2011; Beck et al., 2012). Defining recovery is a personal and focused endeavour; participants in this study believe that they are experts in defining their own journey of recovery.

It is important to note that participants' perceptions of recovery entailed a number of dimensions, some of which relates to previous studies. Participants defined recovery in terms of it being a dynamic, nonlinear process, (Meddings & Perkins, 2002; Jenkins, 2005; Noiseux & Ricard, 2006); minimal and/or absence of triggers or symptoms (Meddings & Perkins, 2002; Mezey, 2010; Lam et al., 2011); ability/motivation to engage/overcome (Leete, 1989; Anthony, 1993; Meddings & Perkins, 2002; Tooth et al., 2003); regaining dignity and self-respect

(Noiseux & Ricard, 2006); taking medication (Thara, 2012) becoming one's previous self, being in control.

Swazi women's description of recovery from the illness of the brain fell predominately within a biomedical parameter. Like previous studies (Jenkins & Carpenter-Song, 2005; Ng et al., 2008; Piat et al., 2009; and Thara, 2012) they stressed the value of taking medication to avoid hospitalisation and promote recovery. This is not the case in other studies (Ridgway, 2001; Noh et al., 2008; Wisdom et al., 2008; Romano et al., 2010; Lam et al., 2011) where people living with the illness of the brain expanded their definition of recovery beyond taking prescribed medication to include other psychosocial aspects. Similar to a number of previous studies (Pejlert et al., 1999; Young & Ensing 1999; Ridgway, 2001; Smith, 2000; Spaniol et al., 2002; Torgalsboen & Rund 2002; Andresen et al., 2003; Knight et al., 2003; Tooth et al., 2003; Jenkins & Carpenter-Song, 2005; Bradshaw et al., 2007; NHS Health Scotland, 2008; Noh et al., 2008; Wisdom et al., 2008; Piat et al., 2009; Romano et al., 2010; Lam et al., 2011; Leam et al., 2011) Swazi women revealed the importance of recovery being a unique and individualised journey, which is best described by those who experience it.

Almost all the Swazi women associated their recovery with the importance of taking medication, emphasising that they would never stop taking their medication because of fear of a decline in their mental state. For some this was an act of compliance, with one participant stating it was because a professional at the hospital told her never to stop taking her medication. A similar trend is evident in other studies (Jenkins & Carpenter-Song, 2005; Ng et al., 2008; Piat et al., 2009; Thara, 2012) where participants described recovery in terms of remission of symptoms, and not taking medication. This is a possible indication of the influence of the medical model in the perception of recovery amongst Swazi women living with the illness of the brain. Studies undertaken by Lam et al (2011) and Ridgway (2001) highlighted the existent conflict between the definition of recovery from medical staff's perspective and that held by



patients living with the illness of the brain. Psychiatrists' definition of recovery was within the parameters of symptom control and compliance with medication, an indication of positive features of the illness with the cure (recovery) being the response to these (Lam et al., 2011). Table 7 below summarizes Swazi women's characteristics of recovery from the illness of the brain that align with those from previous studies.

**Table 7 Recovery: Swazi women's perspective**

<b>Literature review recovery defined (western views)</b>	<b>Participants Views</b>
By those who experience it/ individualized	<b>Winile</b> (I feel better when I feel better) <b>Thobile</b> (I desire to get better) <b>Winile</b> (others with illness...can become better)
Absence/minimal triggers, symptoms, improved mental state	<b>Jojo</b> (means I have a fewer problems), <b>Salaphi</b> (I am not sick anymore), <b>Nono</b> (I'm not irritable) <b>Tenele</b> (not doing bad things), <b>Tholu</b> (I can eat now)
Better is indicated by ability/motivation to engage/overcome	<b>Eli</b> (better when doing various things), <b>Titi</b> (better when doing handcraft), <b>Jojo</b> (I can do a lot of work now), <b>Nono</b> (I do a lot of work now)
Dignity and self-respect	<b>Eli</b> (not stripping naked in public) <b>Tenele</b> (behaving in an acceptable way)
Recovery is a dynamic, nonlinear process	<b>Felaphi</b> (not well recovered from illness) <b>Thobile</b> (gradually...taking baby steps) <b>Nono</b> (I was really not feeling well)
Interpersonal relationships	<b>Nono</b> (my husband does not drink, we now live together in peace and harmony) <b>Felaphi</b> (I chose to live in peace with the people in the community)
Being in control	<b>Winile</b> (not drinking), <b>Selina</b> (taking your tablets), <b>Tholu</b> (make the right choices);
Becoming normal	<b>Hlengiwe; Lulu</b> (being normal) <b>Selina</b> (going back to be yourself) <b>Thobile</b> (I now have normal dreams, no horrifying dreams any more as in the past) <b>Tenele</b> (I then became conscious and normal) <b>Welile</b> (I am better now, I walk normal) <b>Pholile</b> (there you go back to be normal)
Medication	<b>Welile</b> (taking medication and not readmitted to hospital) <b>Hlengiwe</b> (know importance of taking medication; you become well with this medication.) <b>Salaphi</b> (The injection has helped me to be better) <b>Felaphi</b> (became better after the injection) <b>Selina</b> (taking your tablets), <b>Tholu</b> (medication suits me) <b>Winile</b> (The biggest thing is to drink the medication); (this is 20 years since I have been taking these tablets for this illness). <b>Eli</b> (the medication has been very helpful, and I am afraid of stopping to take the medication because I might become unwell again) <b>Jojo</b> (The medication; just give me the medication) ;( nothing else they give me tablets) <b>Lulu</b> (It is the medication. The tablets help me to think properly). <b>Nono</b> (I think the medication is very helpful to me) <b>Tenele</b> (The medication has been very helpful to me) <b>Thobile</b> (The medication is very good, taking my medication has helped me a lot, the tablets helped me to recover from my illness)

## **6.6 Enhancers of recovery from the illness of the brain**

### **6.6.1 At home and in the community**

*“I do know that I could not have made it as far as I have today without the love and support of my family, my therapists, and my friends. It was their faith in my ability to overcome this potentially devastating illness that carried me through this journey.”*  
(Jordan, 1995, p. 11)

The majority of participants in this study appreciated the positive role played by various members of their families and communities in their recovery journey. Recovery from mental illness has been highly associated with the presence of others who serve as a source of support as he or she travels the journey with the person experiencing the illness (Young & Ening, 1999; Warner, 2004). Consequently, family support in developing countries has been noted to play a significant role in enhancing recovery of people living with schizophrenia (Waxler, 1979; Birchwood et al, 1992).

The type of support provided by family and the community to women in this study included; financial, emotional, friendship and companionship. This is a way of promoting recovery as it appeared to enable participants to gain hope, feel valued and included within their families and community. Consequently, a sense esteem that could have become compromised as a result of being stigmatized by others in society was restored.

Many of the participants in my study conveyed a clear sense of contentment from contributing to their communities, in one way or another. A number of them were either in the process of getting involved in supporting orphan children during their mealtimes at the community soup kitchen, or they were already involved. Others talked about their contributions through; cleaning, teaching Sunday school or participating in prayer teams. Besides enjoying fellowship and social inclusion, community involvement promotes recovery from mental illness because it yields feelings of having accomplished something worthwhile, through ‘giving back’ to the

community, while supporting those experiencing the illness through introducing structure into their lives (Bromely et al., 2013).

#### **6.6.1.1 Peer support**

Previous studies have indicated that people living with schizophrenia value the importance of peer support in promoting their recovery, treasuring lessons learnt from each other's journey and developing coping strategies to alleviate the impact of the illness (Roberts & Boardman, 2013). Even though not highlighted by many, one participant talked about the benefits of associating with other people living with illness of the brain. "*We give each other advice, talk about the mental illness*" (Salaphi). Welile's community is pivotal in supporting her identify and deal with triggers of the illness, allowing them to be quickly dealt with without going into relapse in her mental state; "*my neighbours, they can see me when I start being unwell....*" (Welile).

The findings regarding financial support from family and community differ from those revealed in studies done in developed countries, where people living with mental illness receive an allowance from the government. People living with mental illness in Swaziland; do get financial support from the government, hence they need to find employment or find financial support from either the family or community. Arguably, while receiving benefits has been seen as a possible setback to recovery, because patients tend not to seek employment opportunities due to fear of losing their benefits (Bevan et al., 2013), not being able to access benefits, as in Swaziland, can be detrimental to one's health per se as well as to the process of recovery.

#### **6.6.1.2 Religion and faith**

The findings in this study suggest that Swazi women living with the illness of the brain value the support they received from either religious leaders or traditional healers. All participants were either Christians or had faith in traditional healers. Some participants voluntarily visited their church pastors and traditional healers, while others were taken by their relatives or significant others. The value of spiritual support for participants in this study concurs with

findings of previous studies. Most studies conducted amongst BME stated that their trust in God and being connected to religious groups promoted their mental well-being, especially through prayer and sharing their thoughts and feelings with church members (Black et al., 2011; Leamey, 2011; Kalathil et al., 2011). Including religious values in promoting recovery have been found to enhance recovery from mental illness, because those living with mental illness consider religion as a significant integral area of their lives which promotes satisfaction, hope, perseverance, positive sense of self and equips one with beneficial life coping mechanisms (Mizock et al., 2012).

#### ***6.6.1.3 Productivity, Resilient and contentment***

There was a strong notion that participants in this study felt better when involved in productive activities; at home in the community, and at the hospital. While in hospital participants revealed that a positive feature they associated with the illness was that of being able to help others. They expressed feelings of satisfaction and contentment from such engagement, possibly restoring their confidence and self-value, believing they were able to achieve, this appearing to be an important facet of the recovery process (Hoffmann & Kupper, 2002; Pitt, 2007; Romano et al., 2010; Wood et al., 2013).

However, there is a difference in the type of activities equating to achievements participants of previous studies engage in, as opposed to those Swazi women do. This is possibly influenced by the difference in the cultural context and perhaps that of the medical model on their perceptions of recovery. Evidence from previous studies indicate that participants had aspirations for higher achievements, such as going back university (Romano et al., 2010). On the other hand, Swazi women seem to define activities leading to a sense of achievement as those within the sphere of general domestic duties, mostly relating to finding ways of generating income to attend to their basic needs. Doubtless, the higher the self-esteem, the more likely it

is for people recovering from mental illness to be empowered to set and achieve higher goals (Chiba et al., 2010). Being able to accomplish tasks has also been found to enhance the ability to deal with internal stigma, amongst people living with mental illness (Warner, 2009; Lam et al., 2011). While participants in this study alluded to the fact that they sometimes experienced lack of motivation to engage in activities, they used positive self-talk to promote their recovery from the illness of the brain. Additionally, families and significant others encouraged participants to actively deal with the negative feelings and lack of motivation in engaging in work activities (Kennedy-Jones et al., 2005).

While people living with schizophrenia experience recovery from the illness, they remain vulnerable to relapse in their mental state, often affecting their ability to cope with external stressors. However, those who have strong relationships with significant others have been noted to better cope with the hardships of life, and therefore present with less likelihood of becoming mentally unwell (Torgalsboen & Rund, 2010). This study provided insight into the difficulties faced by Swazi women living with the illness of the brain, and how their quality of life could be seriously affected by external stigma.

Even though they acknowledged impediments to their recovery, the majority of the Swazi women were hopeful that their situation could change for the better, with some specifically narrating how they succeeded in dealing with some of the setbacks, which could have or those which hindered their recovery. For example, those who talked about not having enough money also discussed alternative income generating projects. One woman was making plans to go back to school so that she completes her high school education, because she wanted to become a journalist. Due to the fact that she could not sell her hand craft product, Nono started travelling to South Africa where she said her products were on demand.

After experiencing stigmatization, all women remained optimistic and resilient, refusing to be put down by their negative experiences. For example, even though rejected by her husband after she informed him that she had the illness of the brain, Jojo raised her children and talked of being very happy that they had grown up to be helpful and supportive to her. These findings concur with those of a study involving Canadian women, of low social economic status. These women revealed that the health system was not very supportive to their recovery because it focused on their illness, rather than supporting them in dealing with their needs and challenges. However, the women refused to be put down, remaining hopeful that their lives could still be made better (Chernomas et al., 2000; McKay, 2009). A number of people who have lived with mental illness stated that hope is fundamental in their journey of recovery (Zelt, 1981; Lovejoy, 1984; Leete, 1989; Anthony, 1993; Fisher, 1994; Deegan, 1995; May, 2001). Peoples' optimistic attitude and a positive self-esteem have been found to be co-related to their recovery (Beck et al., 2012). Knowing this on the part of staff could be helpful in empowering patients and working with them to devise best ways to promote optimistic values and a positive self-esteem.

*Their sense and excitement of hope and thinking about getting better was actually transferred to myself, such that after most of the interviews I was so excited, returning home and sharing how inspired I was to hear these women's optimistic attitudes, after they had gone through all the challenges of living with the illness of the brain.*

The resilience and optimistic attitude and feelings of hope noted from the Swazi women living with the illness of the brain replicates findings in Chernomas et al.'s (2000) study; *“Despite the expressed difficulty of their lives, these women nonetheless conveyed a pervasive and persistent sense of wanting life to improve and hoping that it could.”* (p. 1520). These findings resonate with and add further evidence to another study showing a strong positive correlation between hope, resilience, empowerment and recovery in people with chronic mental illness living in Japan (Chiba et al., 2010).

While the participants in this study talked about their desires and hopes for a better life in the future, most of their aspirations were focused around returning to normal, doing the things they did prior to their illness, such as being able to help others and doing domestic chores. Two Swazi women talked about higher achievement. As suggested above, one planned to go back to school so that she can study to become a journalist; and another wanted to start a nursery business. However, most of the participants talked about selling fruits and vegetables to get money to attend to their basic need. Even though one of them was a teacher, she seemed desperate for a job so that she was willing to become a cleaner instead. As alluded to earlier participants in other studies, mostly carried out in western society, emphasized accomplishing higher goals, while that of Swazi women was limited to either doing domestic tasks or focusing on small income generating projects.



It is likely that the medical model of thinking limits Swazi women's definition and perception of recovery from the illness of the brain, and as a result this limits their perception of themselves and what they are capable of accomplishing. Another influencing factor could be the lack of employment which causes financial constraints. For Swazi women living with the illness of the brain, perhaps thinking about higher level accomplishments is not a priority, but they would rather think about how they can make ends meet. Believing that one is unable to achieve because of illness is self-restricting and can sometimes be the consequence of paternalism on the part of doctors, nurses, family and significant others. As identified earlier the women in the study were compliant with the medical intervention, and regardless of what they believe in terms of psychosocial factors enhancing their recovery, this is likely to be set against a backdrop of the medical model.

In contrast to this, empowerment is recognised as key in promoting recovery from mental illness. This means having the power to: take personal responsibility, be in control over one's life, focus on strengths, be self-sufficient, grow in confidence, strive for independence, develop a positive self-image, become resilient, be independent and have the courage to persevere (Chernomas et al., 2000; Smith, 2000; Ridgway, 2001; Meddings & Perkins, 2002; Andresen et al., 2003; Knight et al., 2003; Tooth et al., 2003; Jenkins & Carpenter-Song, 2005; Bradshaw et al., 2006; Borg & Davidson, 2008; Piat et al., 2009; Lysaker et al., 2010; Marshall et al., 2009; Kalathil et al., 2011; Wood et al., 2013). Despite all the negative untoward circumstances the participants in this study encounter, they were persistent in wanting to go beyond the limits of the illness to become the best, for their sake, and that of their significant others. As such, I believe that in harnessing such motivation in these women and others living with the illness of the brain could facilitate a new broader perception of recovery within Swaziland. Perhaps, once empowered the women in this study could not only pursue higher goals for themselves, but

might also encourage others to do the same, bringing massive change in society, and in the lives of a multitudes of Swazis and/or other sub-Saharan people living with illness of the brain (Chernmas et al., 2000; McKay, 2010; Manuel, 2012).

## **6.6.2 Hospital**

### ***6.6.2.1 Hospital activities***

While Albert et al. (2011); and Kalathil et al., (2011) highlighted recovery from illness of the brain can happen with or without professional help, other studies have revealed those going through the recovery journey appreciated the support given to them by staff (Pejlert et al., 1999; Tooth et al., 2003; Mancini et al., 2005; Bradshaw et al., 2006; Bradshaw et al., 2007; Noiseux & Ricard, 2008; Ng et al., 2008; NHS Health Scotland, 2008; Noh et al., 2008). Similar findings were identified within this study. A number of participants talked about how they progressively felt better as they participated in ward activities including; playing netball, doing laundry and helping other patients with their physical care needs. A few participants considered it important that they learnt new skills during their hospital admission. In fact, after discharge, Nono tried to use her newly acquired skill of making sleeping mats to generate income for her family. However, this was unsuccessful because of lack the material to start the project.

Engaging in activities, while being an inpatient on a psychiatric ward, has long been recognised as being beneficial to the recovery process. In 1954 Lambo set up the Aro Community Village in Nigeria. The Aro Community Village Experiment (Lambo, 1954) was designed to considered the Yoruba cultural influence in the experience of mental illness and recovery from it. Those who were willing to participate in the therapeutic sessions relocated to the village, accompanied by their next of kin. Firstly, distigmatization and negative attitudes towards people living with mental illness was dealt with by fully involving the next of kin in the treatment process. Secondly, as indicated by Swazi women in this study, self-esteem and self-confidence

of those who participated in various activities within the project was revived (Warner, 2004). Similarly, a more recent study involving BME women in London confirmed the value of working, and how this helped participants' to gain a sense of self-worth (Kalathil et al., 2011). Consumers of mental health services in Australia also appreciated the support given by staff when implementing the Collaborative Recovery Model, indicating that they felt encouraged to take initiative and responsibility in their recovery (Marshall et al., 2009).

The experiences shared by participants in this study, regarding hospital activity engagement brought to light that they learnt new useful skills, enjoyed fellowship and social inclusion, and also found activities to be therapeutic. Thobile talked about how being engaged in activities helped her in dealing with hearing voice, and how she then found meaning to life. According to research conducted in Switzerland, for those recovering from schizophrenia engaging in social activities of their choice resulted in much quicker and steadier recovery (Hoffmann & Kupper, 2002). Even though the Swazi women in this study appreciated engagement in hospital activities, consideration must be given to ensure that such activities promote their recovery, rather than being stressful tasks that have no meaning in their lives. Findings from a study undertaken by Myers (2010), on culture, stress and recovery from schizophrenia, revealed that recovery intended activities exerted stress and strain to the patients they were envisioned to empower. As a result, the use of locally relevant strategies was recommended and noted to yield positive outcome, with patient focused activities promoting self-esteem and enhancing recovery from the illness of the brain (Ridgway, 2001; Hoffmann & Kupper, 2002; McKay, 2010; Wood et al., 2013).

#### ***6.6.2.2 Support from staff***

More than half of the participants valued staff's support with addressing their basic needs of daily living, for example the food provided at the hospital, they verbalized that taking food promoted their recovery by facilitating effective absorption of their medication. Swazi women

emphasised the importance of food and nutrition in terms of gratifying physiological needs. This is not the case in first world countries; and while none of the research papers identified food as an issue in their recovery, it is an important consideration for those providing care in Swaziland and perhaps other third world countries.

There is evidence in the narratives of this study that participants' recovery journey involved personal growth and development. Participants talked about how they either acquired new skills when working at the hospital, and/or how hospital staff supported them in regaining previous skills which had been compromised by the illness of the brain. These findings are in line with those of Tooth et al (2003), Torgalsboen & Rund (2010) where participants indicated the importance of staff's support in promoting their recovery.

#### **6.6.2.3 Medication**

Not taking medication was identified by participants in some previous studies as evidence of their recovery (Jenkins & Carpenter-Song, 2005; Piat et al., 2009; Ng et al., 2008; Thara, 2012). This was not the case in this study. Swazi women strongly associated being better with taking prescribed medication; indicating that relapse in mental state was likely to be a result of not taking prescribed medication. In other words, taking medication seems to have been identified as an enhancer to their recovery. However, this is not very clear. It is possible that participants' perception of taking medication came from fear of what could be conceived as external pressure. Some participants confirmed that staff at the hospital had informed them that they '*must*' take their medication at all times, and never stop. A number of participants stated that even though they felt better, they were never going to stop taking their medication because of '*fear*' that they could become unwell. Another participant said her reason for taking medication was that she was '*following the doctor's rule*' and another said it was because '*my life is in the hands of the doctors.*' This is in contrast to the findings of Kalathil et al.'s (2011) study. While participants acknowledged the benefits of taking prescribed medication, African Caribbean and South Asian women living in London believed the side effects (tremors, weight gain, hair loss)

reduced their self-image and confidence. Consequently, compliance hindered their recovery (Kalathil et al., 2011).

In terms of remission of symptoms, Swazi women seem to have a broader definition of recovery from the illness of the brain. Most of them believed that one is still considered as recovering, even though the symptoms of the illness are present. For example, one participant talked about her desire to return to work and be accepted along with her illness, recognising this could be a gradual process starting with working for a few hours and gradually increasing the time as she became better. Similar findings were revealed in previous studies (Hoffmann & Kupper, 2002; Spaniol et al., 2002; Torgalsboen & Rund, 2002; Albert et al., 2011; Patterson et al., 2011).

#### ***6.6.2.4 The therapeutic talk sessions***

The importance of the time spent chatting with the nurses was highlighted as paramount to the participants' recovery. Nono, for instance, stated that talking with the nurse helped her to think differently about the death of her grandchildren's mother. Talking to the nurse enabled her to reflect on her accomplishments, perhaps instilling hope. The significance of staff's contribution in promoting peoples' recovery by spending time and listening to them, developing strategies of coping and dealing with the hearing of voices, was also identified by patients living with schizophrenia in China, (Ng et al., 2012). Following talking sessions with staff, the participants in this study indicated that they felt a great sense of relief and confidence in dealing with the voices (Ng et al., 2012).

During the interviews, two of the participants mentioned that they benefited from talking about their life world to the researcher. Tholu and Titi linked this experience with how they had felt better after talking with a member of staff at SNPH. I also had an opportunity to use my professional skills to support one of the participants, who became tearful during the interview when talking about how she was beaten with a broom by staff at the hospital. Hopefully, Nono

felt better after talking to me. This incident was reported to the hospital Matron and management for further investigation and intervention.

Similar findings were revealed in a study conducted by Lysaker et al (2010), on personal narratives and recovery from schizophrenia. Exposing their life world to researchers, participants' recovery was augmented by positive feelings such as hope, being valued, increase self-esteem and added sense of self-worth. Consequently, participants felt that they were connected to the rest of society, giving rise to feelings of being included and having a social identity (Repper & Perkins, 2003). Although individualistic and unique, participants' stories can be used to develop scientific knowledge because of their potential to individually *"leaven, challenge, sharpen and enrich the other; each highlights the other's blind spot"* (Roberts, 2000, p. 433). In fact, as a reflect on the above, I realized the importance of 'the therapeutic use of self' of the nurse (Stickley & Freshwater, 2006). While I did little more than listened to their stories, participants' disclosure brought great insight into the importance of active listening and its value to people living schizophrenia.

## **6.7 Conclusion**

Four super-ordinate themes emanated from the exploration of Swazi women's experiences and perceptions of living with the illness of the brain and recovery from it. This chapter discussed the findings within the four super-ordinate themes, along with their sub-ordinate themes against the backdrop of existing literature.

As experts of recovery from the illness of the brain, Swazi women perceived recovery as a unique individualised process. However, their descriptions seem to be limited by the influence of the medical model, so that other psychosocial elements of recovery which were identified in other studies are excluded. Nevertheless, consideration needs to be given to the fact that most

previously published studies originate within western society. Regarding the definition of recovery from the illness of the brain Swazi women seem to experience conflict between what they want or feel defines their recovery, and the medical way of defining it. At times, there is conflict between what they perceive as recovery and how it is perceived by others, especially those considered to be in a supportive role (professionals, family). Where conflict does exist this in turn impacts negatively on their perception of what they believe they are capable of accomplishing.

Swazi women appreciated the support given by staff at the SNPH in terms of; the time they spent talking with them, care and support given, allowing their family members to visit them at the hospital and the administering of medication. However, participants expressed concerns about some paternalistic and coercive practices within the hospital; as reflected in staff's use of language, limited involvement in decision making and often the focus being on medication and symptom relieve. These attributes seem to reflect medically lead clinical practise, and this could be one of the factors which influence Swazi women's description of recovery from the illness of the brain. Likewise, staff also appear to encounter conflict between the constraints of the medical model and what patients' need to promote their recovery from the illness of the brain. It is likely that the medical model is the only approach staff have been exposed to, and as such they are possibly unaware of these conflicts or other frames of reference when considering recovery. Maybe those who are aware lack structure, support and skills in facilitating recovery of the illness of the brain. Paternalism and coercion seems to dominate Swazi psychiatric health care, evident in the language used by staff when communicating with patients, attempts to protect, cure illness, and the use of seclusion. There seems to be a hierarchy of authority, with staff being viewed as more knowledgeable than patients. In the final chapter of my thesis consideration will be given to the implications of the findings from this study will be discussed in the next chapter.

# Chapter 7

## Conclusions and Implications

### 7.1 Introduction

The aim of this hermeneutic phenomenological study was to uncover the experiences, perceptions and meaning of recovery for Swazi women living with a diagnosis of ‘schizophrenia’ named by participants as: “*sifo sengcondvo*,” (transliterated: the illness of the brain). As such, the words will be used interchangeably within this final chapter. In bringing this research to a close I refer to what has already been done, and then indicate how this study and its findings could be used in the future to promote recovery for those living with illness of the brain, in Swaziland. In doing this I will discuss the difference between my initial ‘theory’ and how this has been transformed by the findings of this research. The reiteration, reflection and discussion in this chapter focus on: the purpose of the study; appraisal of the research method; answers to the research questions; implications and recommendations; problems encountered during my research journey; strengths and limitations of the study; recommendations for further research; and the conclusion of the chapter.

### 7.2 Purpose

The purpose of this study was to gain an in-depth understanding of the perceptions, experiences of living with schizophrenia from Swazi women living with this mental illness, and to find out issues that promote and/or hinder their recovery. My passion and desire to conduct this study was aligned with the declaration made by WHO;

*“The message is clear and unequivocal: mental health – neglected for far too long – is crucial to the overall well-being of individuals, societies and countries, and must be universally regarded in a new light” (WHO, 2001, p.63)*

There is no previous research on the perceptions and experiences of people living with the illness of the brain (*sifo sengcondvo*), ‘schizophrenia’, in Swaziland. A homogenous, purposive sample of 15 Swazi women was interviewed at the SNPH, OPD.



This research has answered the research questions regarding the experiences and perceptions of Swazi women living with schizophrenia and recovering from it, what hinders and enhance their recovery: at home, in the community and the SNPH. The added knowledge will be used to: improve: clinical practice, policy design, education, and research. A number of areas which need further exploration through research have been identified within this study, and this will hopefully promote evidence based Swaziland mental health practice.

### **7.3 Research method appraisal**

A discussion on the application of the study's research method to an African community is discussed below, along with learnt lessons, especially regarding bilingual studies, is discussed within this section. A reflection on ensuring rigour within this study is offered, followed by a discussion on recommended topics for further research within this topic area.

#### **7.3.1 Research design**

Choosing the research design was one of the most difficult aspects of this study. In order to be able to choose the relevant theoretical perspective to underpin my study, I had to have an understanding of a range of different philosophical approaches. The lesson I learnt during this process is that reading and re-reading are imperative to successful research. I found that most theorists are not easy to understand, because of the concepts and terminology used. However, dwelling on their philosophies, reading and rereading their theories and papers which adopted one approach or another, gradually enabled me to shed light on what might be an appropriate approach. Below are extracts from my reflective diary made at the beginning of the research, and on one day when, for the first time, I received insight into the theoretical perspective of some of the theorists, which influenced this study.

*Here is the elephant!!!! Where do I start, it is so huge, alive, full of power, potential? I was told to kill it. They gave me their knives, guns, etc. They gave me their email address, telephone numbers, office numbers.... you name it, supposing this will help. But where do I start!!!! Attending some of the lessons, yes, it was good, but I got 1% of what was said.*

*What will happen to me, asking questions in class!!! MMMM...!! let me keep quiet, I might be embarrassed, because I might be the only one who does not know this. Someone else asks the same question, or one to which the answer I know. Oh!!! Others don't know too; I will ask and answer questions tomorrow. The elephant is looking at me, I need to kill this monster. Ehh!!! Procrastinate....I will start tomorrow, time is moving. Do I start with the legs; it might swallow me with its trunk? I should start with the trunk; it will tramp on me with one of its heavy legs. Oh! They gave me their email addresses, their telephone numbers. Ah!!*

#### *Choosing the theoretical perspective of the study*

*The greatest day of this study, so far, when the elephant lost its strength to stand against me, it fell down! Although I had read, read, written, reread and written a lot on the theoretical perspective of my study, and that of other theorists, I have never come to grips with what it meant. Many a time I had either procrastinated or brushed through this section, with the hope that maybe, just maybe there would be a miraculous intervention to my predicament. It was not until one day when I decide that I had no options but to learn and understand the source of my epistemology. This is the day I will never forget. Even though I have not yet won the lottery, this day was marked with unexplainable excitement, that at least my eyes have been opened. I discovered Crotty (1998), and was very comforted when I could acknowledge that this section of this project has two challenges: understanding the heavy jargon of the theorists can be difficult, as well as identifying a theoretical perspective relevant to my study. Even though I had no doubt about my theoretical perspective, understanding it and being able to justify my choice over the others was my predominant challenge. Thanks to Gray (2013), discovering his book led to a vivid understanding of the source at last giving clarity to what it was about. Not that I now know it all now, but at least Crotty helped me reflect on my weaknesses, and Gray added to my limited knowledge on theorists, their influence on my choice of methodology and the data collection strategy.*

Drawing from theorists such as Heidegger, Husserl and Gadamar, I chose phenomenological interpretive analysis in order to obtain an insight into Swazi women's perceptions, experiences and meaning of recovery from schizophrenia. The humanistic value of this approach was relevant as it would enable me to bring new insight into Swazi women's life world; the understanding of Swazi women as intentional beings who are influenced, meaning that they are always conscious of something (Langdrige, 2008). Phenomenology was appropriated in facilitating participants' narration of their consciousness, and the researcher's interpretation and her meaning making of their lived experiences. Because of its roots in phenomenological

theory, mainly hermeneutics, I used IPA to find meaning from their narratives collected during the interviews.

While there are multiple approaches to acquiring reality and lived experiences of others, necessitating rigorous justification of using one over the other, the nature of my research questions would be best answered by the hermeneutic/interpretive phenomenological approach, which in turn inspired my decision to use the IPA. Through this experience, I feel that this approach is relevant for applicability to any socio-cultural context, because it allowed me to engage with both the participants and their stories, and in turn, sustained my interest and motivation to pursue the study while gaining a deep hidden knowledge about the women's experiences, perceptions and meaning of their *lifeworld*. Lowes & Prowse (2001) clearly state;

*“exploration and elucidation of the researcher's interest and emotional investment in a study adds to its significance, not only for the researcher, but in a wider context, for society, of which the researcher is a representative.”* p.475

In other words, it is hoped that this study will add new knowledge, specifically on African women's experiences of recovery from schizophrenia, which, to date there is no evidence to support that such a study has been conducted. The scarcity of research articles on the African perspective of the experiences of women's recovery from schizophrenia indicates a gap in the literature in this significant area. Along with providing additional knowledge, this study will hopefully stimulate other researcher's curiosity, so that more African based studies relating to schizophrenia and recovery will be executed.

I have found that, as Turner et al (2002) argues, the use of a phenomenological hermeneutic theoretical method (similar to all qualitative research methods) and using IPA, have brought the value of serendipitous discovery. This means that researchers must be alert and be open minded in order to identify accidental discoveries; for example, in this study how language and knowing

and not knowing a diagnosis, influenced experiences and perspectives with regard to what recovery entails. Such serendipitous discoveries further add to the body of knowledge.

### **7.3.2 Rigour**

The sample size ended up being larger than planned, and as such I had a lot of data to analyse. While Smith et al (2009) recommends a small sample size of four to six for a novice IPA researcher, he also contends that there is no stipulated number of participants for PhD students, because of the dynamics and unplanned occurrences likely to take place during the research process.

This study only gives findings about women's perceptions and experiences of 'illness of the brain' and their process of recovery from it. Although this is a significant contribution to the existing body of knowledge because it reflects their unique experiences and perspectives, it is perhaps necessary to either conduct other studies focusing on men, and/or which compare both genders. This is fundamental in improving clinical practise, to avoid leaving out the specific needs of each gender.

As most of my participants were not highly educated, and, for geographical reasons, it would have been difficult to communicate with them outside of the study boundaries, it was difficult to check out the authenticity of my interpretation of their narratives given in their mother tongue. As a Swazi woman, I did feel confident in being able to interpret the narratives from siSwati to English, but doing this whilst distancing yourself from the data was not easy. In sitting and listening to the women, and hearing the whole story, I had been influenced by what they said. The involvement of another siSwati speaking mental health professional to cross check the translated interviews, in order to verify that the originality of meaning was maintained, could have strengthened the truthfulness of the findings. As such, I would recommend that subsequent studies conducted in two or more languages bear this in mind.

Researchers almost always present different interpretations of the same text. It is therefore, important for the researcher to cooperatively work with participants to ensure truthfulness of findings. It has also been suggested that participants should have an opportunity to check the interpretation to ensure trustworthiness of findings (Graneheim & Lundman, 2004). However, this it is not without its problems (Burnard et al., 2008). For example, data is collected at a given moment in time and when considered at a different temporal point and as interpreted data the originator may offer another perspective. Burnard et al. (2008) also suggest this might not be feasible as it can be challenging to present the findings to non-academic participants, which was a constraint in this study. Alternatively, the interpretation of the data could raise conscious awareness that was previously denied by the participant, having the potential to cause distress (Warne & McAndrew, 2010). For these reasons, I did not return the interpreted data to the participants. However, this could probably be useful for other research studies.

Dependability was enforced by a detailed description of my research methodology in chapter 3 of this study, so that other researchers could apply the method used in this study, especially within an African socio-cultural context (Guba, 1981). Even if subsequent studies do not yield similar findings the added knowledge brought to the fore by the findings in this study will serve as a source of comparison for other researchers. To ensure conformability I have included an example of an audit trail of one participant in the appendices (appendix J, K, L and M) to show how data was analysed.

The process of reflexivity enhanced rigour and truthfulness of the findings in this study. It appeared that at the beginning of the interview sessions, some of the participants had difficulty in talking about their experiences, but were noted to become confident as the session proceeded.

This was possibly because they were meeting me for the first time, and or the fact that they were revealing personal, maybe embarrassing, painful, experiences. I then spent time at the OPD working with the staff, and this enabled me to establish a rapport with potential participants. Consequently, those who did participate opened up and appeared to freely relate their stories during the interview sessions. In addition, I also realised that the interpretation of participants' definition and description of schizophrenia appeared to have been influenced by the medical model. This was reflected during the interview, and during the analysis. As I listened, read and re-listened and read their stories, immersing myself into their lifeworld, I realised, for example that I was constantly referring to their experience of living with schizophrenia, yet none of the participants talked about schizophrenia. I have already discussed this issue in previous chapters; however, it is of great significance to note that had it not been for reflexivity, this new knowledge would not have been revealed.

### **7.3.3 Sensitivity to context**

The researcher's ability to be sensitive to context has been described by Yardley (2000) as one of the measures of authenticity in qualitative research. Considering the fact that people living with illness of the brain are vulnerable, I obtained permission to conduct this study from the University of Salford and from the Government of Swaziland. The one to one interview sessions were conducted by the researcher, and took place at the OPD, an environment familiar to participants. Because of the likelihood of bringing up sensitive issues during the interview, I allocated time where I used professional therapeutic skills to support participants who needed such support. This was applied during one session where one of the participants became tearful as she talked about how she was beaten by staff during her admission at the SNPH.

Using qualitative research methods to explore recovery from illness of the brain was beneficial because it facilitated a shift in my thinking, from one of emphasising the illness to focusing on the person (Sells et al., 2004). By sharing the same words (language) it is hoped that the

participants' voices were brought to the fore, and will perhaps provide an opportunity to develop model of recovery, relevant to Swazi women living with a diagnosis of schizophrenia, and possibly one that could be transposed to other women in the sub-Saharan region Africa (Holloway & Wheeler, 1996; Silverman, 2010).

I have learnt a few lessons from collecting data during this research study. First, the importance of in-depth interviews versus collecting shallow data from a number of participants is key to understanding others' lived experiences. As previously stated, as the interviews progressed so did my ability to gain more in-depth knowledge. I was initially fearful of doing research interviews, would I ask 'the right' questions, would the audio recorder work, would the women speak to me, all these questions might have led to me rushing a couple of the early interviews. However, as I settled within myself I believe my interview technique improved and perhaps the women felt more at ease to share their experiences.

Secondly, the issues of conducting research in two languages became a challenge in this study, mainly because this was not considered at the beginning of the project, and therefore, no plans or preparations were made. However, it appears that this became an area of added knowledge, particularly because no similar study has been done. Thirdly, although there is no siSwati word for schizophrenia, I assumed participants would describe the illness using the same medical term. This is one area where I realised the significance of reflexivity through supervision and personal reflection. Thus, now we know that Swazi women perceive themselves to be living with illness of the brain, and not with schizophrenia, the latter only being used by staff at the SNPH.

#### **7.4 Living with Sifo sengcondvo (The Illness of The Brain)**

Swazi women have announced their bio-psychosocial name for schizophrenia – “*sifo sengcondvo*”; and have revealed the struggles associated with living with the illness of the brain. As indicated by others (Leete, 1989; Jordan, 1995), living with the illness of the brain brings a lot of emotional challenges, and changes in behaviour, which in turn makes it difficult to live with others; at home and in the community. Unlike other studies (McKay, 2010; Mezey et al., 2010, Chadwick, 2011; Kalathil et al., 2011; Lam et al., 2011) where people living with mental illness have actually identified themselves with their given diagnosis, findings revealed that participants in this study consider themselves to be living with the illness of the brain: ‘*sifo sengcondvo*’ rather schizophrenia, the medical diagnosis written in their medical records.

Perhaps, these findings indicate the need for compassionate support and integration of the medical model and psychosocial model in promoting the recovery of people living with the illness of the brain in Swaziland, with special consideration being given to the socio-cultural influence on living with the illness, and recovering from it.

#### **7.5 Kubancono (being better)**

Participants in this study described recovery as “*being better*” from the illness of the brain. Taking medication was viewed as important because it prevented hospital admission. Swazi women revealed the importance of recovery being a unique, an individualised journey or process, which is best described by those who experience it. Most participants considered recovery in terms of ‘going back to normal’ function as before the illness. A few of the women perceived recovering with symptoms as part of their journey.



While Swazi women living with the illness of the brain have goals and ambitions to accomplish during the recovery journey, their goals are mostly those of being capable to perform domestic duties and being able to support others. Even though these are important, it is likely that such goals are influenced by their limited perception of what they can accomplish, and possibly scarcity of financial resources.

## **7.6 Hindrances to recovery**

Participants talked about how their recovery from illness of the brain is hindered, within three areas: community, home and at the SNPH.

### **7.6.1 Community & Home**

The recovery of Swazi women living with illness of the brain is hindered by the experience of stigma and coercion from family members who wrongly labelled them as mentally unwell, and imposed their values and beliefs regarding managing the illness. One lady was forcefully given traditional medicine at home, because her brother in law was a traditional healer, yet she did not want to take the traditional medicine. Another lady was also forcefully sent to the hospital because she was found dancing at her in laws' homestead, where she lived. Dancing at the in-laws would have been interpreted differently should it have been a man dancing at his in-laws, and it is likely that he would not have been forced to go to the hospital.

One of the emergent themes which hinder Swazi women's recovery from illness of the brain was discrimination from employers, a situation which exacerbated the already existing financial constraints, a situation shared in other parts of the world (Thornicroft et al., 2009; Lam et al., 2011). After indicating she wanted to return to work because she felt better, one of the participants reported that her employer denied her an opportunity to work by repeatedly procrastinating over her date of return to work. While financial constraint is a general challenge to most Swazi women, this is a source of further hindrance to the recovery of those living with the illness of the brain, as due to the stigma attached to mental illness it is often not acceptable

for them to return to work. This is problematic as monetary constraint has been found to be common to most people living with mental illness (Manuel et al., 2012; Smith, 2000; Spaniol et al., 2002).

### **7.6.2 Hospital**

The Swazi women involved in this study indicated that they were not involved in their care, for example, in the decision to be sent to seclusion. The findings suggest that the medical model and coercive treatment have a strong influence on mental health practice in Swaziland; and from the patients' point of view, this hindered their recovery. Participants felt that their time was wasted by being forcefully given treatment and interventions which were not beneficial to their well being. For example, a few participants talked about how they felt '*dragged down by the injection*' which was coercively administered to them. There is need for the development of clear guidelines on using seclusion and prescribing medication and better monitoring of people once admitted to SNPH. Additionally, the environment in seclusion must be therapeutic and made conducive to the process of recovery.

Recovery at the hospital was further hindered by some of the negative language used by staff, which is possibly an indication of staff being judgemental, and their desire to show patients that they are in authority. This made participants' feel belittled and humiliated, and as such hindered their recovery process. Likewise, the use of seclusion is not conducive to promote recovery from 'illness of the brain' and may reinforce the notion of staff having authority, or worse power over patients. The environment in which seclusion took place was also not conducive to recovery, with participants feeling isolated and believing they had been unfairly sent to seclusion. At a more pragmatic level the environment poses risks to hospital-acquired infections, because of poor sanitation and lack of basic facilities, such as a mattress and blankets. Participants also reported that they sometime missed their meals because they were

served after other patients, when food would have been finished, perhaps being poorly nourished and increasing their vulnerability to infection.

## **7.7 Enhancers of Recovery**

### **7.7.1 Community and home**

Family and significant others are key to the recovery of people living with ‘illness of the brain’; this included support in terms of finance, listening, being involved and identification of triggers and symptoms of the illness. In addition to all the above, the community enhanced recovery by making the participants to feel included within community activities, such that, one woman stated, *“I even forgot that I have the illness of the brain.”*

### **7.7.2 Hospital**

Participants showed appreciation of some services provided by hospital staff during their hospital admission; including early identification of a decline in their mental state, immediate intervention, and supporting them in meeting their needs for daily living. Most participants were grateful for staff’s support in re-learning social skills which had been affected by the illness of the brain. Other participants’ valued time spent by staff; encouraging them to write about their experiences of the illness, talking with them about the illness, helping them to develop coping strategies, dealing with stressors and exploring how they could enhance their recovery process. Some participants also reported that being involved in hospital activities, and going out to the community, involvement of their significant others (family), taking medication at the right time also enhanced their recovery from illness of the brain. Participants would like to have community-based services. One participant recommended attending monthly reviews at places nearer to where they live could be beneficial, not only to their recovery, but could also save them the money spent in travelling to the hospital.

## **7.8 Implications and Recommendations**

Findings from this study have given rise to the following implications and recommendations, and these will be discussed within mental health practise, policy, research and education. It is

hoped that recovery of people living with the illness of the brain could be facilitated by strengthening participants' enhancers of their recovery and deliberately working on those things which impedes their recovery.

### **7.8.1 Practice**

#### ***7.8.1.1 Transforming clinical practice***

This study recommends the need to strengthen community services that enhance recovery from the illness of the brain. This will hopefully help in supporting more people in the community, and reduce hospital admissions at the SNPH. As indicated at the beginning of this project, the SNPH is the only 150 bed mental health hospital in Swaziland and it is overcrowded, with over 400 patients admitted (WHO, 2011) at any given time. Among the high number of inpatients seem to be hospitalised when perhaps more localised services could provide opportunity for them to continue to recover in the community. Institutionalisation enforces medical values and dependency on others, mainly on professionals to 'cure' one's illness. As such, the health professionals are viewed (by themselves and patients) as superior, so that their decisions about patients' care and progress is absolute (Munetz & Frese, 2001). I will illustrate this using a reflection from my personal experience.

*One of my relatives was admitted into the psychiatric hospital four weeks before I travelled to Swaziland. Assessing her on my arrival at the hospital, I realised that she was mentally stable so that I could support her at home, and appeared to be oversadated with medication. She also she cried, stating that she wanted come home with me, and that the medication "do nothing for me but make me sleep." It was Friday and staff were very reluctant to release my sister to go on leave, informing me that the doctor was not available until Monday. Staff also informed me that I was not going to manage taking care of my sister because of her previous incident of violence, which led to her admission. Two hours later after realising that I was not going to leave my relative at the psychiatric hospital that day, staff phoned the doctor and my sister went home that day. She has now completed her second degree and has recently been accepted at a university to pursue her master's degree in health economics.*

While this is a one person's example, perhaps it accentuates the need to for the mental health services to employ the recovery model in supporting people living with the illness of the brain.

One element of the model is the belief that people living with the illness of the brain have the

potential to become better, and they are responsible for their own destiny, with others supporting them through the journey (Unzicker, 1989; Houghton, 1982; McDermott, 1990; Deegan, 1998; Allott, & Loganathan, 2002). Ralph (2000) emphasised the significance of a paradigm shift to all personnel dealing with mental health issues (researchers, administrators, policy makers) in order to yield positive outcomes in their endeavours to promote recovery. This would require a situation whereby professionals relinquish their ‘expert’ care coordinating role of being in control and acknowledge of patients’ ability to manage themselves and being in control of their own destiny (Ralph et al., 2002; Allot et al., 2003; May, 2003). Consequently, this paradigm shift would lead to huge financial savings of the already over stretched government funds, and also ease stress experienced by patients and staff alike that is likely to be inherent in an overcrowded hospital.

The context for this study is Swaziland, the smallest country hit hardest by HIV/AIDS. Considering the context of this study, and comments made by two participants, regarding living with schizophrenia and HIV/AIDs, it appears significant to pay attention to the physical health needs of people living with co-existing health problems in Swaziland. Deinstitutionalisation, improving mental and physical health assessment and appropriate management of medication for people living with co-existing illnesses should be key strategies to reducing the already high rates of premature death in this group of people (Shean, 2010).

#### ***7.8.1.2 Empowering practise: to individuals***

This study supports the argument for a change in health professionals’ way of thinking about patients. Mental health practice in Swaziland appears to be mostly dominated by the biomedical model, and this is likely to have an influence on professionals’ way of interacting with patients, but it also seems to influence participants’ perception of their recovery from illness of the brain. Professionals who view people living with the illness of the brain as having potential to fulfil their dreams, goals and desires have actually helped them accomplish their dreams, and

instilling hope. Therefore, changing practise in Swaziland mental health services to one whereby the medical, psychosocial and cultural aspects of peoples' lives become the focus for providing care, hopefully maximising patients' potential and enhancing their recovery. Instead of having decisions regarding their care imposed upon them, patients would be fully involved, and given autonomy to become their very best. Their decisions would be valued, considered and respected, with staff offering their expertise with regards to interventions and working in collaboration to ascertain the best pathway for their recovery. This will enhance recovery from illness of the brain by promoting collaboration and partnership, so that patients would be recognised as experts in their care and treatment, as well as in decision making.

People living with schizophrenia in other parts of the world have indicated the importance of others' belief and support in their recovery journey. They have also talked about how they have been empowered by being encouraged to be autonomous and responsible for their destination as they go through the recovery journey (Lovejoy, 1982; Fisher, 1994; Deegan, 1998; Leete, 1998; Hewitt & Coffey, 2005; McGuire-Snieckus et al., 2007). Due to the stigma revealed by participants, mental health practitioners can help to boost the self-esteem of Swazi women by empowering them in such areas as dealing with the illness, and recovering from the internal stigma. This means that professionals must be good listeners in order to identify the unique hindrances of recovery from individual patients, working with them to identify strategies of dealing with their specific issues.

Swazi women living with illness of the brain would like to engage in productive activities, mainly to earn income so that they are able to attend to their basic needs and those of their significant others. However, it is possible that such ambitions are aborted due to lack of information and support in pursuing their dreams. The findings of this study recommend that mental health professionals should work in collaboration with other community agencies to

support people living with illness of the brain to either find gainful employment and/or return to work. Participants in this study expressed the desire to return to work. This means that mental health professionals should advocate for the strengthening of the role of community organisations in supporting the acquisition of skills and employment. One example is the Manzini Bosco Skill centre which is located not far from the SNPH and could work more collaboratively with the hospital to aid the process of recovery.

Following the findings that people living with illness of the brain experience tension within themselves, it is important that those working with this group provide empathetic non judgemental support. This means strengthening and/or teaching counselling skills to mental health professionals, and all who support those with such experiences.

#### ***7.8.1.3 Empowering practise: to the community and family***

Following participants' experience of stigma at home, in community and at the workplace, I recommend that information regarding mental illness be dissemination through the media (radio and television), with the hope that this would transform negative attitude towards people living with illness of the brain (Dixon, 2004; Parle, 2012). All communications must focus on inculcating positive mental health messages. The contact based approach is probably the best strategy in fighting societal stigma, mainly co-opting the help of young people living with the illness of the brain. Using the contact base approach implies that people living with the illness of the brain share their stories of the illness and their recovery journey with lay members of society (Stuart, 2005). This initiative will hopefully change society's attitudes and myths towards people living with the illness of the brain.

The positive aspects of developing countries revealed in various studies, such as the IPSS (Sartorius et al., 1974; Harrison et al., 2001) should be used to strengthen recovery from people

living with the illness of the brain in Swaziland. This means that mental health practises should provide support and counselling to families of people living with illness of the brain. This could be done by showing empathetic understanding of the distress of caring for a mentally ill person, information sharing regarding the person's condition, treatment and how they can best support their relative.

With the establishment of a rehabilitation programme, as discussed above, community groups and activities, which provides support and inclusion for people living with the illness of the brain, could be identified and strengthened in order to facilitate community integration and inclusion. This will hopefully not only support individuals and families, but will also help deal with issues of stigmatisation for those living with the illness of the brain, by promoting a change of attitude and removing the myths surrounding mental illness (Stuart, 2005).

All in all, this study recommends that in order to promote the recovery of people living with illness of the brain in Swaziland, mental health professionals must integrate the use of medication (antipsychotic drugs) with evidence-based psychosocial interventions (Shean, 2010), and must set out a flexible rehabilitation programme within SNPH. While the dominant feature of care is currently based on the medical model, there is need to introduce an alternative model, integrating the psychosocial aspects of promoting recovery from mental illness. This could take the form of staff within the hospital focusing on this as their priority in providing it and/or the development of units acting as a links between the hospital and the community, accommodating the development of skills that would better enhance a process of recovery better recognised in the 'outside world'.



#### **7.8.1.4 Evaluating SNPH recovery services**

As a way of evaluating the extent to which the SNPH is effectively implementing and delivering recovery oriented services, and based on the findings of this study, I recommend the use of the following indicators;

1. A partnership is evident between professional-patient, patients are fully involved in planning and decision making throughout their care.
2. The attitude of staff providing care for people with illness of the brain is positive.
3. Rather than diagnosis, staff have good insight into what lead to the person's admission, their story forming the core of the assessment, with account being taken of their emotional state, feelings and experience of the illness.
4. Empowering patients, through information sharing regarding the illness, interventions, and the development of coping strategies to deal with the challenges they face.
5. Patients' personal values and beliefs are supported, with emphasis being placed on helping them to achieve their aspirations.
6. Individualised care planning in place and can be demonstrated for all patients.
7. Staff recognise and focus on patients' strengths, and provide positive reinforcement of all accomplishments.
8. Peer support has been established and used to enhance positive thinking in terms of recovery.

#### **7.8.2 Policy/stakeholders**

This study suggests that at policy level, emphasis must be made to address physical and mental health issues equally; giving equal priorities to both areas of life. This means that there would be identical allocation of the financial budget for both physical and mental health. Policies must be designed with the view of improving the quality of life for people living with illness of the brain, such as those which will promote equal employment opportunities. It's best to start with local policies, then move to those at the national level (Stuart, 2005).

In addition to the above the findings of this study have wider implications than health per se. Evidence has been provided indicating the need for health to work more closely with other agencies; governmental and none governmental. For example the Ministry of Agriculture could help to devise strategies to sustain peoples' income by generating projects which could help meet their nutritional needs. A number of participants talked about their desires to grow crops for family consumption and/or to sell to others. However, one of the mian challenges to this is the lack of a steady water supply, so crops die because of extreme heat.

National policies should be formulated in a way that indicate non-discrimination work practises. Since permission to conduct this study was granted by the government of Swaziland, Ministry of Health, I will provide them with a written report of this study, including the findings and recommendation on how to improve mental health practise in the country. Initial dialogues will be held with the hospital matron and nursing sisters. This will lead to the development of a forum with the minister of health and other relevant agencies (for example WHO, Swazialnd) considering and monitoring good practice and eradicating bad practice.

### **7.8.3 Research**

As a result of this study, important areas of missing knowledge have been identified, so that this can be addressed through additional research being undertaken within these areas. As such, findings of this study could be used to inform additional research. For example, (1) Are the needs of men and women experiencing illness of the brain different? (2) Would the setting up of community mental health units within Swaziland relieve the pressure on beds at SNPH and/or provide cheaper, more accessible care to those that need it? (3) If specialist recovery units were introduced into the Swazi mental health care system would staff attitudes towards illness of the brain change? (4) Would the introduction of a locally delivered education programme regarding

mental illness change societal attitudes towards those deemed to suffer from such illness? [Also see section 7.8.5 'Further research']

### ***7.8.3.1 Problems arising during the research***

1. There is limited African perspective information on mental illness and recovery. In light of this the majority of information used in the literature review was based on the either developed countries, or other developing countries (China, India) rather than African countries.
2. The challenge of using two languages in a research study and keeping fidelity to the women's' narratives.
3. Being a novice researcher, I needed to reassess my interview technique and build a rapport with potential participants. This strategy better facilitated the telling of the stories of those who did decide to take part in the study. This lead to me gaining detailed in-depth insight into their experiences, and consequently there was a lot of data to be analysed taking a lot more time than planned.
4. A male participant diligently asked to be involved in the study, yet he did not meet the criterion. I was unable to reiterate my criteria and interviewed him as a gesture of good will rather than staying focused on my research.
5. Due to the type of participants in this study (living with illness of the brain), in order to ensure conformability, I constantly had to return to the recorded interview for clarity. However, some parts of their stories remained unclear, so that some significant information could have been missed.
6. While the researcher is at liberty to add his or her view regarding participants' experiences, during interpretation, I encountered challenges regarding the extent to which I would do this, because there is no demarcation between the researcher's interpretation and that of the participants. For example, when one of the participants talked about her boyfriend

drinking alcohol in front of her, and telling her that she was not invited, I summarised this was a cause of embarrassment for her. On reflection I realised that the participant did not talk about being embarrassed, but this was my assumption.

#### **7.8.4 Education**

In order to promote recovery focused practice, I recommend that the health curriculum be reviewed to evaluate the extent to which the concept of recovery based interventions from the illness of the brain is taught to student nurses and all other health professionals and, if necessary to develop it. Curricula should be designed not only to reveal the findings of this study, but to enlighten and in still hope to aspiring professionals, that people living with illness of the brain do recover from this illness. Findings from this study will influence designing curricula, which will produce health professionals suitable to support patients' recovery from the illness of the brain, within the African cultural perspective (specifically Swaziland).

For example, some of the recovery models (Wellness recovery action plan, the modified star recovery model) discussed in chapter one should be taught to pre-and post graduate nurses'. Students could be supported to test the relevance of these models, and these could be adopted according to the cultural needs of Swazi people. Students would have an opportunity to learn about autobiographies of people from different parts of the world who have shared their experience of living with mental illness. In addition, Swazis with lived experience of illness of the brain could be invited into the classroom to share their stories, and hopefully encourage students not only to change their perceptions of people living with illness of the brain, but to also have hope that recovery is possible.

#### **7.8.5 Further research**

In addition to the above, the following areas could be considered for future research;

- Experiences of significant others on living with people living with mental illness. This is important because it could hopefully reveal how they could be best supported to be more effective in their support for the patients.
- Nurses'/doctors' attitudes and perceptions of recovery from mental illness, a measure of their knowledge and identification of gaps, this could possibly have an influence on informing patients about their diagnosis, its impact on recovery and self-concept.
- Studies on issues around seclusion, for example, patients' perceptions of recovery and the influence of seclusion to their recovery from illness of the brain.
- Although not the focus of this study, two participants made comments about the coexistence of HIV/AIDs and illness of the brain. Further studies on HIV/AIDS and mental health/illness might be significant in promoting recovery, especially in promoting the inter-relatedness of physical and mental health.
- The effects of integrating other Government ministries and other agencies with mental health, for example, Agriculture, to ensure all needs of those with illness of the brain are met and opportunities for maximising a better quality of life are available.

## **7.9 Conclusion**

This is the first phenomenological study which investigated Swazi women's perspectives of recovery from illness of the brain. Using the IPA to analyse data, along with the research method gave me the liberty to subjectively, yet systematically interpret and analyse data, making it

applicable to use even within the confines of the Swazi culture. This has given a rich insight into participants' life world. Findings could be used to develop an African based model of recovery, and further studies could be conducted in its effectiveness so that adaptations could be employed to suit specific societies/cultures.

In keeping with a number of studies on people living with schizophrenia, the participants in this study revealed that they experienced stigmatisation; at home, in the community and at the SNPH. An insight into the Swazi women's feelings and experience of the treatment received at the hospital has been discussed. The environment and treatment in seclusion and staff's use of unpleasant language have been identified as some of the hindrances to their recovery. The majority of participants believed that recovery from the illness of the brain is possible, acknowledging that (like others with lived experience of schizophrenia) it is an individual unique process.

Similar to some studies undertaken among African participants living in developed countries, the women in this study appreciated the positive contributions given by their families in their recovery journey. The findings also revealed that the recovery of Swazi women living with the illness of the brain was enhanced by contentment, which they said was received from a number of sources, among which are; reflecting on previous accomplishments, trust in God, and having hope that things would actually get better.

This study revealed the need to introduced recovery focused services in Swaziland. Such services will promote or make it possible for staff to provide bio-psychosocial culturally sensitive interventions in supporting people living with illness of the brain. Staff training, ongoing supervision and the contact based approach will hopefully unveil hope for people living

with illness of the brain; to individuals, professionals and members of the community. The government of Swaziland will hopefully save money by implementing deinstitutionalisation strategies. Promoting a progressive link between community supportive services and the SNPH is inevitable in promoting recovery from illness of the brain.

Conducting further research in areas identified within this study will not only provide evidence based practise, but will promote collaborative and quality care to people living with illness of the brain. These findings will also be used to disseminate information to patients, families and the general public, in an attempt to promote awareness of mental illness and hopefully reduce stigma. Improving knowledge, educating staff at a higher level would promote critical thinking and a change of focus from the medical model to one that encompasses the psychosocial needs of those living with illness of the brain. Workshops seminars could be used to continue education regarding recovery, and ongoing supervision is a strategy which could be used to enhance reflective practise and promote a change of attitude among staff's.

## **7.10 Finally**

I would like to end this study, first by bringing out some of the participants' narrations which transformed my attitude, knowledge and perception of patients living with mental illness. Secondly, I have extracted a quote from my reflective diary which emphasis that without undertaking this study, I would not have been changed as a person. I do hope that those who read this thesis will not only gain new knowledge, but that they would, perhaps appreciate the significance of implementing a bio-psycho-socio-cultural recovery based model to those living with illness of the brain, their significant others and funders of mental health services in Swaziland.

### **7.10.1 Participants' quotes**

#### **WINILE:**

*"I have illness of the brain.....They teach us that when you plant you can get beetroot, you can get spinach, those green vegetable, but..... we are not able to water the*

*plants.....they then died.....we cook together, sit down to eat the food together, this makes me feel very happy, I feel that I am better in my mind. Indeed, I forget that I have an illness of the brain..... Even though in the community they refuse to let me do some of the activities because they say I have an illness of the brain, but at home I am very happy, and I am accepted.”*

**WELILE:**

*“Some take me wrongly; they think I am mad all the time..... They use to beat use at the hospital.... the odals..... Some nurses also joined in..... They could beat you and lock you into seclusion.....For me to be taken to seclusion it was unfair, I was defending myself....”*

**SALAPHI:**

*“I did not like it at home though when they brought me to the hospital stating that I was unwell, yet I was well..... I saw everything that was done to me, I remember everything, they did not tell the truth, they made up a liar. I remember very well everything; I shouldn't have been brought to hospital.”*

**PHOLILE:**

*“I did tell the doctor that I was not ill. But they continued to hold me and injected me. I told them that I was okay..... this lady told the people that I was not well, and they took me in a car and brought me to hospital.....*

**TITI:**

*I don't like the seclusion. That room is very small.*

**THOLU:**

*“..... volunteers who came to the hospital to help us learn how to bake. This was very helpful to me. I also played netball in the hospital..... my friends and I would be allowed to go out for some hours to the local shops.....it was great fun.....”*

**THOBILE:**

*“I want my employer to allow me to do thing gradually, he should not tell me to stop working, but should let me do things at a slower pace. I have spoken to my employer and suggested this, he told me to wait, and thinks that I am still not feeling well. However, this is a problem....”*

**TENELE:**

*“I was beaten by staff in the hospital.....I did not tell anyone about this. They forced me to go to seclusion, I refused to go.”*

**JOJO:**

*“The medication. It is good, but they sometimes change my tablets, and they don't sometimes. They have been changing my medication here at the hospital, sometimes I took four, on other occasions I could take three. Now it is much better because I take two tablets, one in the morning and one at night.”*

**SELINA:**

*“The tablets help me to have a sound mind; I am able to perform many domestic duties and can observe all the signs of road safety when walking around....”*



**NONO:**

*".....I also talked with another nurse ..... discussed my feelings and stress. This nurse talks like you..... I was really worried and grieving.....This nurse.....encouraged me ..... The nurse asked me what I work..... The nurse encouraged me to continue making the mats..... and not to put a lot of pressure on myself..... I have put this into practice and this has been very helpful."*

**LULU:**

*"I am not involved in any activity in the community but would like to participate in the community orphan feeding program" in my area. I feel I able capable of taking care of children.*

**LONDI:**

*"There is no such thing as becoming better."*

**FELAPHI:**

*"During my admission in hospital, nurses were observant, they realised that I had a disturbed sleeping pattern and gave me medication that helped to sleep; this made me to be more stable in the brain. I wonder how they saw this, and I realised that nurses and staff at this hospital are caring.....we are usually quickly attended by staff at the hospital, we do not have to wait for longer period before being seen."*

**ELI:**

*"I see a lot of improvement in this hospital; people are becoming better now than before. Staff now talk to us, they give us the medication, there treatment in this hospital has improved."*

***A reflection on the impact of this study to the researcher:***

*This being a phenomenological hermeneutic study, that took IPA to analyse data, I can confess, sometimes with shame and embarrassment, that before this study my clinical practise and interaction with patients living with the illness of the brain was influenced by the medical model. At times my attitude toward patients was that of being in a position of 'power' and 'knowing.' For example, I have mostly judged people living with the illness of the brain as unable to talk sensibly, and I have thought as one participant stated 'that they are always mentally unwell' so that I presumed they needed support from others, including decision making. I believed that they had no capacity, so that others should make decisions on their behalf. This study has change my attitude in many ways; mainly to viewing people living with the illness of the brain as experts, so that collaborative care is one of the important aspects of promoting their recovery. Consequently, my passion for promoting recovery has escalated through this project and by immersing myself in participants' stories; those of this study and from previous research. On the other hand, it could be argued that such transformation could have been realised through continuing professional development; yet, doing this PhD has given me an opportunity to read, write and reflect extensively. As a result, my knowledge has been increased, and my attitude has been changed. For me, the greatest reward is to see the dreams of those thought to be 'going no-where' come to fruition, and being part of their support through their recovery journey.*

## References

- Albert, N., Bertelsen, M., Thorup, A., Petersen, L., Jeppesen, P., Le Quack, P., & Nordentoft, M. (2011). Predictors of recovery from psychosis: analyses of clinical and social factors associated with recovery among patients with first-episode psychosis after 5 years. *Schizophrenia research*, 125(2), 257-266.
- Allen, R. E., Fowler, H. W., & Fowler, F. G. (1990). *The Concise Oxford dictionary of current English*. Oxford: Clarendon Press.
- Allott, P., Loganathan, L. & Fulford, K.W.M. (2003). Discovering hope for recovery: a review of a selection of recovery literature, implications for practice and systems change in Lurie, S., McCubbin, M., & Dallaire, B. (Eds.). International innovations in community mental health [special issue]. *Canadian Journal of Community Mental Health*, 21(3).
- Alonso-Betancourt, O., & Morales-Herrera, M. (2010). Community rehabilitation for schizophrenia patients: Is it feasible in South Africa?. *South African Journal of Psychiatry*, 16(3), 2.
- Anders, L. S. (2003). Improving Community-Based Care For The Treatment of Schizophrenia: Lessons from Native Africa. [Literature review, Africa and developed countries]. *Psychiatric Rehabilitation Journal*, 27(1), 51-58.
- Andreasen, N. C. (1999). A unitary model of schizophrenia: Bleuler's fragmented phrene as schizencephaly. *Archives of general psychiatry*, 56(9), 781-787.
- Andresen, R., Oades, L., & Caputi, P. (2003). The experience of recovery from schizophrenia: towards an empirically validated stage model. *Australian and New Zealand Journal of Psychiatry*, 37:586-594. [Literature review]
- Angermeyer, M. C., & Matschinger, H. (2005). Causal beliefs and attitudes to people with schizophrenia. *The British Journal of Psychiatry*, 186(4), 331-334.
- Anthony, W. (1993). Recovery from Mental Illness: The Guiding Vision of the Mental Health Service System in the 1990s. *Rehabilitation Journal*, 1993, 16(4), 11-23
- Armour, M., Peterson, B. W., & Roseborough, D. (2009). African Americans and Recovery from Severe Mental Illness. *Social Work in Mental Health*, 7(6), 602-622.
- Attride-Stirling, J. (2001). Thematic networks: an analytic tool for qualitative research. *Qualitative Research* 1(3), 384-405. doi: 10.1177/146879410100100307
- Baker, M. (1992). A coursebook on translation. *LMJ London and New York: Rout-ledge*.
- Baker, S. E., & Edwards, R. (2012). *How many qualitative interviews is enough?* National Center for Research Methods. Available at: <http://eprints.ncrm.ac.uk/2273/>
- Barbour, R.S. (1999). The Case for Combining Qualitative and Quantitative Approaches in Health Services Research. *Journal of Health Services Research Policy* 4(1): 39-43
- Baker, S. & Strong, S. (2001). Roads to recovery: How people with mental health problems recover and find ways of coping. London: Mind.

- Beck, R., Heffernan, S., Law, H. Mccusker, M., Bentall, R. P., & Morrison, A. P. (2012). Subjective judgements of perceived recovery from psychosis. *Journal of Mental Health, 21*(6), 556-566. doi: 10.3109/09638237.2012.710765
- Bellack, A. S. (2006). Scientific and consumer models of recovery in schizophrenia: concordance, contrasts, and implications. *Schizophrenia bulletin, 32*(3), 432-442.
- Benner, P. E. (Ed.). (1994). *Interpretive Phenomenology*. California: SAGE Publications, Inc.
- Bevan, S. Gulliford, J., Steadman, K., Taskila, T. Thomas, R. and Moise, A. (2013) Working with Schizophrenia: Pathways to Employment, Recovery & Inclusion
- Bhugra, D. (2005). The Global Prevelence of Schizophrenia. *Perspectives 2*(5), 0372-0373.
- Biggerstaff, D., Thompson, A. R. (2008). Interpretative Phenomenological Analysis (IPA): A Qualitative Methodology of Choice in Healthcare Research. *Qualitative Health Research in Psychology, 5*(3), 214-224. doi: 10.1080/14780880802314304
- Birbili, M. (2000). Translating from one language to another. Social Research Update, 31. Retrieved January 20, 2014, from <http://www.soc.surrey.ac.uk/sru/html>
- Birchwood, M., Cochrane, R., Macmillan, F., Copestake, S., Kucharska, J., & Carriss, M. (1992). The influence of ethnicity and family structure on relapse in first-episode schizophrenia. A comparison of Asian, Afro-Caribbean, and white patients. *The British Journal of Psychiatry, 161*(6), 783-790.
- Black, H. K., Gitlin, L., & Burke, J. (2011). Context and culture: African-American elders' experiences of depression. *Mental Health, Religion & Culture 14*(7), 643-657.
- Borg, M., & Davidson L. (2008). The Nature of Recovery as Lived in Everyday Experience. *Journal of Mental Health. 17*:129-40.
- Botha U. A., Koen, L., & Niehaus D. J. (2006). Perceptions of South African schizophrenia population with regards to community attitudes towards their illness. [Research Paper]. *Social Psychiatry & Psychiatric Epidemiology, 41*, 619-623.
- Bradshaw W, Armour MP, Roseborough D. (2007). Finding a place in the world: the experience of recovery from severe mental illness. *Qualitative Social Work, 6*(1):27-47.
- Bradshaw, W., Roseborough, D. & Armour M.P. (2006). Recovery from Severe Mental Illness: The lived Experience of the Initial Phase of Treatment. *The International Journal of Psychosocial Rehabilitation, 10*(1), 123-131.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101. doi: 10.1191/1478088706qp063oa
- Brislin, R. W. (1970). Back-translation for cross-cultural research. *Journal of Cross-Cultural Psychology, 1*, 185-216
- Brocki, J. M., & Wearden, A. J. (2006). A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychology and Health, 21*(1), 87-108. doi: 10.1080/14768320500231085

- Bromley, E., Gabrielian, S., Brekke, B., Pahwa, R., Daly, K. A., Brekke, J. S., & Braslow J. T. (2013). Experiencing Community: Perspectives of individuals Diagnosed as Having Serious Mental Illness. *Psychiatric Services*, 64(7), 1-14. doi: 10.1176/appi.ps.201200235.
- Brown, C., & Lloyd, K. (2001). Qualitative Methods in Psychiatric Research. *Advances in Psychiatric Treatment*, 7, 355-356. doi: 10.1192/apt.7.5.350
- Burnard, P., Gill, P., Stewart, K., Treasure, E., & Chadwick, B. (2008). Analysing and presenting qualitative data. *British Dental Journal* 204(8), 429-432. doi: 10.1038/sj.bdj.2008.292
- Burns, B. (2000). *Introduction To Research Methods*. London: SAGE Publications Ltd.
- Burns, J. K. (2010). Mental health services funding and development in KwaZulu-Natal: A tale of inequity and neglect. *South African Medical Journal*. 100: 662-666
- Burns, J. K. (2011). The mental health gap in South Africa—a human rights ISSUE. *The Equal right review*, 6(99-113)
- Burns, N & Grove, SK. 1999. *Understanding Nursing Research*. Philadelphia: WB Saunders.
- Burr, V., (2001). *An Introduction to social constructionism*. New York: Routledge.
- Bush, G. "Proclamation 5956 - Education Day, U.S.A., 1989 and 1990," April 14, 1989. Online by Gerhard Peters and John T. Woolley, *The American Presidency Project*. <http://www.presidency.ucsb.edu/ws/?pid=23514>. Retrieved 12/03/2015
- Calabrese, J. D., & Corrigan, P. W. (2005). 'Beyond Dementia Praecox: Findings from Longterm Follow-up Studies of Schizophrenia', in Ralph, R and Corrigan, P (eds) *Recovery in mental illness: Broadening our understanding of wellness*, Washington, DC: American Psychological Association, Chapter 3
- Care Quality Commission Report (2012/13). Retrieved from [https://www.cqc.org.uk/sites/.../documents/cqc\\_mentalhealth\\_2012/13](https://www.cqc.org.uk/sites/.../documents/cqc_mentalhealth_2012/13), On 06/04/2015.
- Cha, E.-S., Kim, K. H., & Erlen, J. A. (2007). Translation of scales in cross-cultural research: issues and techniques. *Journal of Advanced Nursing*, 58(4), 386-395. doi: 10.1111/j.1365-2648.2007.04242.x
- Chadwick, L. (2011). *Investigating Recovery in Psychosis: a Personal Construct Repertory Grid Study*. (PhD), University of Hertfordshire, South-East England.
- Chapman, E. & Smith, J. (2002). Interpretive Phenomenological Analysis and the New Genetics. *Journal of Health Psychology* 7(2) 125-130
- Chang, A. M., Chau, J. P., & Holroyd, E. (1999). Translation of questionnaires and issues of equivalence. *Journal of advanced nursing*, 29(2), 316-322.
- Chen., H.Y., & Boore, J. R. P. (2009). Translation and back-translation in qualitative nursing research: methodological review. *Journal of Clinical Nursing*, 19, 234-239. doi: 10.1111/j.1365-2702.2009.02896.x

- Chernomas, W. M., Clarke, D. E., Chisholm, F. A. (2000). Perspectives of women living with schizophrenia. *Psychiatric Services*, 51(12), 1517-1521.
- Chiba, R., Miyamoto, Y., & Kawakami, N. (2010). Reliability and validity of the Japanese version of the Recovery Assessment Scale (RAS) for people with chronic mental illness: scale development. *International journal of nursing studies*, 47(3), 314-322.
- Chovil, I. (2005). Reflections on Schizophrenia, Learned Helplessness/Dependence, And Recovery. *Psychiatric Rehabilitation Journal*, 29(1), 69-71.
- Chovil, I. (2005). Reflections on Schizophrenia, Learned Helplessness/Dependence, and Recovery. *Psychiatric Rehabilitation Journal*, 29(1), 69-71.
- Cohen, M., Z., Kahn, D., L., & Steeves, H. R. (2000). *Hermeneutic Phenomenological Research A Practical Guide for Nurse Researchers*. London: Libray of Congress Cataloging-in-Publication Data.
- Cohen, A., Patel, V., Thara, R., Gureje, O. (2008). Questioning an axiom: better prognosis for schizophrenia in the developing world? *Schizophrenia Bulletin Journal*, 34, 229–44.
- Collier, E. (2010). Confusion of recovery: One solution. [Literature review]. *International Journal of Mental Health Nursing*, 19, 16-21.
- Collier, E., Yates-Bolton, N. (2011). Older people in mental health care. Chapter 20 p239-249. *Mental Health Ethics. The human context*. Routledge, Oxon.
- Corbin, J., & Strauss, A. (2008). *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory* (3rd ed.). Thousand Oaks, CA: Sage
- Corrigan, P.W. & Watson, A.C. (2002). Understanding the impact of stigma on people with mental illness. *World psychiatry*, 1(1),16-20.
- Crabb, J., Stewart, R.C., Kokota, D., Masson, N., Chabunya, S., and Krishnadas, R. (2012). Attitudes towards mental illness in Malawi: a cross-sectional survey. *BioMed Central Public Health*, 12(541), 1-6.
- Creswell, J. W. (2003). Creswell, J. W. (2003). *Research design: Qualitative, quantitative, and mixed methods approaches* (2nd ed.). Thousand Oaks, CA: Sage.
- Creswell, J. W. (2007). *Qualitative Inquiry & Research Design* (2nd Edition ed.). California: Sage Publications Inc.
- Creswell, J. W. (2013). *Research design qualitative, quantitative and mixed approaches* (4<sup>th</sup> edition). Los Angeles: Sage Publications Inc.
- Crist, J. D., & Tanner, C. A. (2003). Interpretation/ Analysis Methods in Hermeneutic Interpretive Phenomenology. *Nursing Research*, 52(3), 202-205.
- Cronin, P., Ryan, F., & Coughlan, M. (2008). Undertaking a literature review: a step-by-step approach. *British journal of nursing*, 17(1), 38.
- Crotty, M. (1998). *The foundations of social science research: meaning and perspective in the research process*. New South Wales: Allen and Unwin.

- Crotty, M. (1996). *Phenomenology*. Melbourne: Churchill Livingstone
- Davidson, L. (1994). Phenomenological Research in Schizophrenia: From Philosophical Anthropology to Empirical Science. *Journal of Phenomenological Psychology*, 25(1), 105-130.
- Davidson, L. (2003). *Living Outside Mental Illness: Qualitative studies of recovery in schizophrenia* (forwarded by Strauss J. S). New York University Press: New York.
- Davidson Larry, L. M. S., & Leary Fiona. (2005). Concepts of recovery: competing or complementary? [Literature review]. *Current Opinion in Psychiatry*, 18, 664-667.
- Deber, R. B., Kraetschmer, N., Urowitz, S., & Sharpe, N. (2005). Patient, consumer, client, or customer: what do people want to be called?. *Health Expectations*, 8(4), 345-351.
- Deegan, P. (1988). Recovery: The lived experience of rehabilitation. *Psychosocial Rehabilitation Journal*, 9(4), 11-19.
- Deegan, P. (1995). Recovery as a journey of the heart. *Psychiatric Rehabilitation Journal*, 19(3), 91-97.
- Deegan, P. (1996). Recovery as a journey of the heart. *Psychiatric rehabilitation journal*, 19(3), 91.
- Denzin, N., & Lincoln, Y. (Eds.). (2005). *The SAGE handbook of Qualitative Research* (3rd ed.). Thousand Oaks: Sage Publications.
- Denzin, N., & Lincoln, Y. (Eds.). (2011). *Handbook of Qualitative Research* (4th ed.). California: SAGE Publication Ltd.
- Dickens, G., Weleminsky, J., Onifade, Y., & Sugarman, P. (2012). Recovery Star: validating user recovery. *The Psychiatrist Online*, 36(2), 45-50.
- Dinos, S., Stevens, S., Serfaty, M., Weich, S., & King, M. (2004). Stigma: the feelings and experiences of 46 people with mental illness. *The British Journal of Psychiatry*, 184(2), 176-181.
- Dixon, J. K. (2004). Instrument translation process: a methods review. *Methodological issues in nursing research*, 48(2), 175-186.
- Dowling M (2007) From Husserl to van Manen: a review of different phenomenological approaches. *International Journal of Nursing Studies*, 44, 131-42.
- Eatough, V., Smith, J.A. & Shaw, R. (2008). Women, anger and aggression: An interpretative phenomenological analysis. *Journal of Interpersonal Violence*, 23, 1767-1799.
- Economou, M., Palli, A., Peppou, L., Madianos, M. (2011). Recovery from Schizophrenia: A Four-year Study of an Inner City Cohort. [Research]. *Community Mental Health Journal*, 47, 660-667. doi: 10.1007/s10597-011-9390-0
- Fade, S. (2004). Using interpretative phenomenological analysis for public health nutrition and dietetic research: A practical guide. *Proceedings of the Nutrition Society*, 63, 647653

- Farrokh, P. (2011). The Equivalence and Shift in the Persian Translation of English Complex Sentences with wh-Subordinate Clauses. *English Language and Literature Studies*, 1(2), 74.
- Finlay, L. (2009). Ambiguous encounters: A relational approach to phenomenological research. *Indo-Pacific journal of phenomenology*, 9(1), 1-17.
- Fisher, D.B. (1996). Self-managed care: The most cost-effective managed care. *National Empowerment Centre Newsletter*, Spring.
- Fleming V, Gaidys U and Robb Y (2003) Hermeneutic Research in Nursing: Developing a Gadamerian-based Research Method *Nursing Inquiry* 10, 2, 113 – 120.
- Fossey, E., Harvey, C., McDermott, F., & Davidson L. (2002). Understanding and evaluating qualitative research. *Australian and New Zealand Journal of Psychiatry*, 36, 717-732.
- France, C. M. & Uhlin, B. D. (2006). Narrative as an outcome domain in psychosis. *Psychology and Psychotherapy: Theory, Research and Practice*, 79: 53–67. doi:10.1348/147608305X41001
- Frisch, N. C., & Frisch, L. E. (2006). *Psychiatric mental health nursing*. New York: Thomson Learning.
- Galbin, A. (2014). An Introduction To Social Constructionism. *Social Research Reports*, 26, 82-92.
- Geanellos, R. (2000). Exploring Ricoeur's hermeneutic theory of interpretation as a method of analysing research texts. *Nursing Inquiry*, 7 (2), 112-119.
- Gergen, K. J. (1985). The social constructionist movement in modern psychology. *American Psychologist*, Vol 40(3).
- Gerrish, K., & Lacey, A. (Eds.). (2010). *The Research Process in Nursing* (6th ed.). West Sussex: Blackwell Publishing Ltd.
- Glover, H. (2012). Recovery, lifelong learning, empowerment & social inclusion: is a new paradigm emerging? In: Ryan, P., Ramon, S., & Greacen, S. (eds.) *Empowerment, Lifelong Learning and Recovery in Mental Health: Towards a New Paradigm*. London: Palgrave. Oxford: Wiley-Blackwell.
- Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse education today*, 24(2), 105-112.
- Gray, D. E. (2013). *Doing research in the real world*. London: Sage.
- Guba, E.G. (1981), Criteria for assessing the trustworthiness of naturalistic inquiries, *Educational Communication and Technology Journal* 29 (2) 75–91 7591. doi: 10.1007/bf02766777
- Gureje, O., Chisholm, D., Kola, L., Lasebikan, V., & Saxena, S. (2007). Cost-effectiveness of an essential mental health intervention package in Nigeria. *World Psychiatry*, 6:42– 48.

- Gwen, D. (2005). Coping with Mental illness. [Personal Experience narrated]. *Psychiatric Rehabilitation Journal*, 28(3), 299-302.
- Harding, C.M., Brooks, G.W., Takamaru, A., Strauss, J.S., Breier, A. (1987) The Vermont Longitudinal study of persons with severe mental illness II: Long-term outcome of subjects who retrospectively met DSM-III criteria for schizophrenia. *American Journal of Psychiatry* 144(6),727-735.
- Harrison, G., Hopper, K., Craig, T., Laska, E., Siegel, C., Wanderling, J., Dube K. C., Ganey, K., Giel, R., An Der Heiden, W., Holmberg, S.K., Janca, A., Lee, P. W. H., Leon, C. A., Malhotra, S. Marsella, J. A., Nakane, Y., Sartorius, N., Shen, Y., Skoda R., Thara, R., Tsirkin, S.J., Varma, V.K., Walsh, D., & Wiersma, D. (2001). Recovery from psychotic illness: a 15- and 25-year international follow-up study. *British Journal of Psychiatry* 178, 506-517. doi: 10.1192/bjp.178.6.506 (WHO study)
- Harrow, M., Grossman, L., Jobe, T., & Herbener, E. (2005). Do patients with schizophrenia ever show periods of recovery? A 15-year multi-follow-up study. *Schizophrenia Bulletin* 31, 723–734.
- Harrow, M., & Jobe, T. H. (2005). Longitudinal Studies of Outcome and Recovery in Schizophrenia and Early Intervention: Can They Make a Difference? *The Canadian journal of Psychiatry*, 50(14), 879-880.
- Harrow, M., Jobe, T. H., Faull, R. N. (2012). Do all schizophrenia patients need antipsychotic treatment continuously throughout their lifetime? A 20-year longitudinal study. *Psychological Medicine* 42, 2145–2155.
- Heidegger, M. (1962) *Being and Time*. (Translated Macquane, J., & Robinson, E.). Oxford: Basil Blackwell.
- Hewitt, J. & Coffey, M. (2005). Therapeutic working relationships with people with schizophrenia: literature review. *Journal of Advanced Nursing*, 52(5), 561-570. doi:10.1111/j.1365-2648.2005.03623.x
- Hoffmann., & Kupper Z., (2002). Facilitators of Psychosocial recovery from schizophrenia. *International Review of Psychiatry*. 14, 293-302.
- Holloway, I., and Freshwater, D., (2007). *Narrative Research in Nursing*. Oxford: Blackwell Publishing.
- Holloway, I., & Wheeler, S., (1996). *Qualitative Research for Nurses*. London: Blackwell Science Ltd.
- Hopper, K., Harrison, G., Janca, A., & Sartorius, N. (2007). Recovery from schizophrenia: An international perspective. A report from the WHO Collaborative Project, the International Study of Schizophrenia. *Annals of Clinical Psychiatry*, 19(3), 209.
- Houghton, J.F. (1982) First Person Account: Maintaining mental health in a turbulent world. *Schizophrenia Bulletin*, 8(3), pp. 548-553.
- Hsieh, H. F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, 15(9), 1277-1288.



- Hsin-Chun Tsai, J., Choe, J.H., Mu Chen Lim, J., Acorda, E., Chan N. L., Taylor, V., Tu Shin-Ping. (2004) Developing Culturally Competent Health Knowledge: Issues of Data Analysis of Cross-Cultural, Cross-Language Qualitative Research. *International Journal of Qualitative Methods*, 3(4): 16–27.
- Hugo, C. J., Boshoff, D. E. L., Traut, A., Zungu-Dirwayi, N., & Stein, D. J. (2003). Community attitudes toward and knowledge of mental illness in South Africa. [Qualitative study]. *Social Psychiatry & Psychiatric Epidemiology*, 38, 715-719. doi: 10.1007/s00127-003-0695-3
- Husserl, E. (1950). *Cartesian Meditations: An Introduction To Phenomenology* (D. Cairns, Trans.). London: Martinus Nijhoff Publishers.
- Imonioro, O. (2009). The Recovery Star model and cultural competency. Report of the Recovery Star BAME Pilot Study Mental Health Providers Forum. Downloaded from <http://www.mhpf.org.uk/RecoveryStarResources.asp> on 03 April 2013.
- International Mental Health Research Organisation (2010). Report of the strategic Review Group. Downloaded from <https://www.imhro.org/about-imhro> on 25 June 2015.
- Jablensky A, Sartorius N, Ernberg G, et al. (1992) Schizophrenia: manifestations, incidence and course in different cultures. A World Health Organization ten-country study. *Psychol Med Monogr Supp.* 20:1-97
- Jenkins, J. H., Carpenter-Song, E. (2005). The New Paradigm of Recovery from Schizophrenia: Cultural Conundrums of Improvement without cure. *Culture, Medicine and Psychiatry*, 29, 379-413.
- Jenkins, J. H., Strauss, M. E., Carpenter, E. A., Miller, D., Floersch, J., & Sajatovic, M. (2005). Subjective experience of recovery from schizophrenia-related disorders and atypical antipsychotics. *International Journal of Social Psychiatry*, 51(3), 211-227.
- Jones K., M., Cooper, J. and Fossey, E. (2005) Developing a worker role: Stories of four people with mental illness. *Australian Occupational Therapy Journal*, 52(2), p116126. doi: 10.1111/j.1440-1630.2005.00475.x
- Jones, E. G., & Boyle J. S. (2011). Working with Translators and interpreters in research: Lessons Learned. [Review of Literature]. *Journal of Transcultural Nursing*, 22(2), 109-115. doi: 10.1177/1043659610395767
- Jordan, Janice C. (1995). The first person account: Schizophrenia-From Adrift in an Anchorless Reality *Schizophrenia Bulletin*, (21) 3.
- Kalathil, J. (2011) Recovery and resilience: African, African Caribbean and South Asian women's narratives of recovering from mental distress. London: Mental Health Foundation and Survivor Research. *Archive of mental health recovery stories*, accessed June 7, 2014, <https://mentalhealthrecovery.omeka.net/items/show/80>.
- Kearney, R. (2007). Paul Ricoeur and the hermeneutics of translation. *Research in phenomenology*, 37(2), 147.
- Kelly, M., & Gamble, C. (2005). Exploring the concept of recovery in schizophrenia. *Journal of Psychiatric & Mental Health Nursing*, 12, 245 – 251.

- people with mental illness. *Australian Occupational Therapy Journal*, 52(2), 116-126.
- Killaspy, H., Marston, L., Omar, R. Z., Green, N., Harrison, I., Lean, M., ... & King, M. (2012). Service quality and clinical outcomes: an example from mental health rehabilitation services in England. *The British Journal of Psychiatry*, bjp-bp.
- Knight, M., Wykers, T., Hayward, P. (2003). 'People don't understand': An investigation of stigma in schizophrenia using Interpretative Phenomenological Analysis (IPA). [Interpretative Phenomenological Analysis - Research study]. *Journal of Mental Health*, 12(3), 209-222. doi: 10.1080/0963823031000118203
- Knox, D. K., & Holloman, G. H. (2012). Use and Avoidance of Seclusion and Restraint: Consensus Statement of the American Association for Emergency Psychiatry Project BETA Seclusion and Restraint Workgroup. *Western Journal of Emergency Medicine*, 13(1), 35-40. <http://doi.org/10.5811/westjem.2011.9.6867>
- Kondrat, D. C., & Teater, B. (2009). An anti-stigma approach to working with persons with severe mental disability: seeking real change through narrative change. [Literature review]. *Journal of Social Work Practice*, 23(1), 35-47.
- Kopelowicz, A., Ventura, J., Liberman, R. P., & Mintz, J. (2007). Consistency of Brief Psychiatric Rating Scale factor structure across a broad spectrum of schizophrenia patients. *Psychopathology*, 41(2), 77-84.
- Kreyenbuhl, J. Robert W. Buchanan, R.W., Dickerson, F. B., Dixon, L.B. (2010). The Schizophrenia Patient Outcomes Research Team (PORT): Updated treatment recommendations 2009. *Schizophrenia Bulletin*, 36(1), p. 94-103, 2010. doi:10.1093
- Kulhara, P., & Chakrabarti, S. (2001). Culture and schizophrenia and other psychotic disorders. *Psychiatric Clinics of North America*, 24(3), 449-464.
- Lam, M. M. L., Pearson, V., Ng, R. M. K., Chiu, C.P.Y., Law, C.W., & Chen, E. Y. H. (2011). What does recovery from psychosis mean? Perceptions of young first-episode patients. *International Journal of Social Psychiatry*, 57(6), 580-587.
- Lambo, J. A. (1955). Role of cultural factors in paranoid psychosis among the Yoruba tribe. *Journal of Mental Science*, 101, 239-266.
- Langdridge, D. (2007). *Phenomenological Psychology. Theory, Research and Method*. London. Pearson Prentice Hall.
- Langdridge, D. (2008). Phenomenology and critical social psychology: Directions and debates in theory and research. *Social and Personality Psychology Compass*, 2, 11261142.
- Larkin, M., Watts, S. & Clifton, E. (2006). Giving voice and making sense in Interpretative Phenomenological Analysis. *Qualitative Research in Psychology*, 3, 102-120.
- Larkin, P. J., de Casterlé, B. D., & Schotsmans, P. (2007). Multilingual translation issues in qualitative research reflections on a metaphorical process. *Qualitative health research*, 17(4), 468-476.

- Laverty, M. S. (2003). Hermeneutic Phenomenology and Phenomenology: A Comparison of Historical and Methodological Considerations. *International Journal For Qualitative Methodology*, 2(3), 21-35.
- Leamy, M., Bird, V., Le Boutillier, C., Williams, J., & Slade, M. (2011). Conceptual framework for personal recovery in mental health: systematic review and narrative synthesis. *The British Journal of Psychiatry*, 199(6), 445-452.
- Le Boutillier, C., Leamy, M., Bird, V. J., Davidson, L., Williams, J., & Slade, M. (2011). What does recovery mean in practice? A qualitative analysis of international recovery-oriented practice guidance. *Psychiatric services*.
- Lee, C. C., Li, D., Arai, S., & Puntillo, K. (2008). Ensuring cross-cultural equivalence in translation of research consents and clinical documents: A systematic process for translating English to Chinese. *Journal of Transcultural Nursing*.
- Leete, E. (1989). How I perceive and Manage My Illness. *Schizophrenia Bulletin*, 15(2), 197-200.
- Lowes L, & Prowse, M. A. (2001) Standing outside the interview process? The illusion of objectivity in phenomenological data generation. *International Journal of Nursing Studies* 38, 471-480.
- Liberman, P. & Kopelowicz, A. (2002). Recovery from schizophrenia: A challenge of the 21 century. *International Review of Psychiatry*, 14, 245-255.
- Lopez, K. A., & Willis, D. G. (2004). Descriptive Versus Interpretive Phenomenology: Their contributions to nursing knowledge. *Qualitative Health Research*, 14(5), 726-735. doi: 10.1177/104973204263638
- Lovejoy, M. (1982). Expectations and the recovery process. *Schizophrenia Bulletin*, 8(4), pp. 605-609.
- Lowes, L., & Prowse, A. (2001). Standing outside the interview process? The illusion of objectivity in phenomenological data generation. *International Journal of Nursing Studies*, 38, 471-480.
- Lyons, C., Hopley, P., & Horrocks, J. (2009). A decade of stigma and discrimination in mental health: Plus ça change, plus c'est la même chose (the more things change, the more they stay the same). *Journal of Psychiatric & Mental Health Nursing*, 16, 501-507.
- Lysaker Paul H., L. R. S., & Lysaker John T. (2003). Narrative transformation as an outcome in the psychotherapy of schizophrenia. [Literature Review]. *Psychology and Psychotherapy: Theory, Research and Practice*, 76, 285-299.
- Lysaker, P. H., Ringer, J., Maxwell, C., McGuire, A., & Lecomte, T. (2010). Personal narratives and recovery from schizophrenia. *Schizophrenia research*, 121(1), 271-276.
- Mackey, S. (2005). Phenomenological nursing research: methodological insights derived from Heidegger's interpretive phenomenology. *International journal of nursing studies*, 42(2), 179-186.

- Mancini, M. A., Hardiman, E. R., & Lawson, H. A. (2005). Making sense of it all: consumer providers' theories about factors facilitating and impeding recovery from psychiatric disabilities. *Psychiatric rehabilitation journal*, 29(1), 48.
- Mangalore R, Knapp M. (2007) Cost of schizophrenia in England. *Journal of Mental Health Policy Economics*. 10(1), 23-41
- Manuel, J. I., Hinterland, K., Conover, S. & Herman, D. B. (2012). "I Hope I Can Make it Out There": Perceptions of Women with Severe Mental Illness on the Transition from Hospital to Community. *Community Mental Health Journal*, 48, 302-308. doi: 10.1007/s10597-011-9442-5
- May, R. (2004) Understanding psychotic experience and working towards recovery. In *Psychological Interventions in Early Psychosis* (eds P. McGorry & J. Gleeson). Chichester: Wiley in press.
- Marshall, S. L., Oades, L. G., & Crowe, T. P. (2009). Mental health consumers' perceptions of receiving recovery-focused services. *Journal of Evaluation in Clinical Practice*, 15, 654-659. doi: 10.1111/j1365-2753.2008.01070.x
- Mason, J. (1996). *Qualitative Researching*. London: Sage.
- Mental Health Providers Forum, 2008. Mental Health Recovery Star Organisational Guide. Downloaded from: <http://www.mhpf.org.uk/sites/default/files/rsvaildatinguserrecovery> on 11 04 2014
- May, T. E. (2003). *Qualitative Research in Action*. London: SAGE Publication.
- McAndrew S., Chambers M., Nolan F., Thomas B. & Watts P. (2014) Measuring the evidence: Reviewing the literature of the measurement of therapeutic engagement in acute mental health inpatient wards. *International Journal of Mental Health Nursing*, 23, 212 – 220
- McDermott, B. (1990). Transforming depression. *The Journal*. 1(4), pp. 13-14.
- McGrath, J., Saha, S., Chant, D., & Welham, J. (2008). Schizophrenia: a concise overview of incidence, prevalence, and mortality. *Epidemiologic reviews*, 30(1), 67-76.
- McGuire-Snieckus, R., McCabe, R., Catty, J., et al. (2007) A new scale to assess the therapeutic relationship in community mental health care: STAR. *Psychological Medicine*, 37, 85–95.
- McKay, E. (2010). ‘Rip that book up, I’ve changed’: Unveiling the experiences of women living with and surviving enduring mental illness. *British Journal of Occupational Therapy*, 73(3), 96–105.
- McLynn, D. (1996). Making sense of schizophrenia. *Practice Nursing*, 7(9): 15-18.
- McNamara, M. S. (2005). Knowing and doing phenomenology: The implications of the critique of 'nursing phenomenology' for a phenomenological inquiry: A discussion paper. *International Journal of Nursing Studies*, 42, 695-704. doi: 10.1016/j.ijnurstu.2005.02.002
- Meddings, S. & Perkins, R. (2002). What ‘getting better’ means to staff and users of rehabilitation service: an exploratory study. *Journal of mental health*, 11(13), 319-325.

- Menninger, J. A. (2001). "Involuntary treatment: Hospitalization and medications." *Jacobson, James L. y Jacobson, Alan M.; Psychiatric Secrets, second edition. Philadelphia, PA: Hanley & Belfus, Inc*, 477-484.
- Merriam, S. B. (2002). Introduction to qualitative research. *Qualitative research in practice: Examples for discussion and analysis, 1*, 1-17.
- Mezey, G. C., Kavuma, M., Turton, P., Demetriou, A., & Wright, C. (2010). Perceptions, experiences and meaning of recovery in forensic psychiatric patients. *The Journal of Forensic Psychiatry & Psychology*, 21(5), 683-696. doi: 10.1080/14789949.2010.489953
- Ministry of Health. (1983) Swaziland Government: National Health Policy. MOH, Mbabane.
- Miao, J. (2006). Translation Competence Research—the Basis of Translation Teaching Model Construction. *Foreign Language and Their Teaching*, 4, 47-50.
- Mizock, L., Millner, U.C., & Russinova, Z. (2012). Spiritual and Religious Issues in Psychotherapy with Schizophrenia: Cultural Implications and Implementation. *Religions*, 3, 82–98. doi:10.3390/rel3010082
- Moran, D. (2002). *The phenomenology reader*. Psychology Press.
- Morse, J., M., Barrett, M., Mayan, M., Olson, K., & Spiers, J. (2002). Verification Strategies for Establishing Reliability and Validity in Qualitative Research. *International journal of Qualitative Methods*, 1(2), 1-19.
- Mosotho, L., Calitz, F.J.W. & Esterhuyse, K.G.F. (2008). Clinical manifestations of mental disorders among Sesotho speakers. [Comparative study]. *International Journal of Psychiatry in Clinical Practice*, 12(3), 171-179. doi: 10.108/13651500701794012
- Munetz, M. R., & Frese, III, F. J. (2001). Getting Ready For Recovery: Reconciling Mandatory Treatment with the Recovery Vision. *psychiatric Rehabilitation Journal*, 25(1), 35-42.
- Munhall, P., L., (1994). *Revisiting Phenomenology*. New York: National League for Nursing Press.
- Myeni, A. D., & McGrath, E. . (1990). Swaziland: perspectives on school health. *Journal of School Health* 60(7), 351-356.
- Myers, N. L. (2010). Culture, Stress and Recovery from Schizophrenia: Lessons from the Field for Global Mental Health. *Culture, Medicine and Psychiatry*, 34, 500-528. doi: 10.1007/s11013-3010-9186-7
- Ng, P., Chun, R. W. K., & Tsun, A. (2012). Recovering from hallucinations: A qualitative study of coping with voices hearing people with schizophrenia in Hong Kong. *The Scientific World Journal*, 1-8. doi: 10.1100/2012/232619
- Ng, R.M.K., Pearson, V., Lam, M., Law, C.W., Chiu, C. P.Y., & Chen, E.Y.H. (2008). What does recovery from schizophrenia mean? Perceptions of long-term patients. *International Journal of Social Psychiatry*, 54(2), 118-130.
- NHS Health Scotland (2008). Scottish Recovery Network Health in Mind. NHS Lothian Minority Ethnic Mental Health Project. Saheliya Outside the Box.

- NICE. (2009). Schizophrenia: core interventions in the treatment and management of schizophrenia in primary and secondary care. NICE Clinical guideline 82. London: National Institute for Health and Clinical Excellence
- Noh, C., Choe K., & Yang, B. (2008). Hope From the Perspective of People with Schizophrenia (Korea). *Archives of Psychiatric Nursing*, 22(2), 69-77.
- Noiseux, S., & Ricard N. (2008). Recovery as perceived by people with schizophrenia, family members and health professionals: A grounded theory. *International Journal of Nursing studies*, 45, 1148-1162.
- Oaks D., Director (2012.) Let's Stop Saying "Mental Illness"! *Mind Freedom International*. Down loaded from: [www.mindfreedom](http://www.mindfreedom) on 17/7/14
- Ono, Y., Satsumi, Y., Kim, Y., Iwadate, T., Moriyama, K., Nakane, Y., ... & Someya, T. (1999). Schizophrenia: is it time to replace the term?. *Psychiatry and clinical neurosciences*, 53(3), 335-341.
- Onwuegbuzie, A. J., Leech, N., Collins, K. M. (2012). Qualitative Analysis Techniques for the Review of the Literature. *The Qualitative Report*, 17 (56) 1-28
- Opie, A. (1992). Qualitative research, appropriation of the 'other' and empowerment. *Feminist review*, (40), 52-69.
- Panou, D. (2013). Equivalence in translation theories: A critical evaluation. *Theory and Practice in Language Studies*, 3(1), 1.
- Paolo Fusar-Poli, M. D., & Politi, P. (2008). Paul Eugen Bleuler and the birth of schizophrenia (1908). *American Journal of Psychiatry*.
- Paquette, M. & Navarro, T. (2005). Editorial: Lives recovered. *Perspectives in Psychiatric Care*. 2005; 41(3):95– 96.
- Papadopoulos, A., Fox, A., & Herriott, M. (2013). Recovering wellbeing: an integrative framework. *British Journal of Mental Health Nursing*, 2(3), 145-154.
- Parle, S. (2012). How does stigma affect people with mental illness?. *Nursing times*, 108(28), 12.
- Patterson Tess, M. R., Gale Christopher & Gray Andrew. (2011). Compulsory community treatment and patients' perception of recovery in schizophrenia. *Psychiatric Services*, 19(5), 431-433.
- Pearson, A. (2004). *Recovery: Challenging the Paradigm (a consumer perspective)*. Paper presented at the Vicserve Conference, Melbourne, Australia.
- Peebles, S. A., Mabe, P. A., Davidson, L., Fricks, L., Buckley, P. F., & Fenley, G. (2007). Recovery and Systems Transformation for Schizophrenia. *Psychiatric Clinics of North America*, 30(3), 567-583.
- Pejlert, A., Asplund, K., & Norberg, A. (1999). Towards recovery: living in a home-like setting after the move from a hospital ward. *Journal of Clinical Nursing*, 8(6), 663-674.

- Penn, D. L. & Nowlin-Drummond, A. (2001) Politically correct labels and schizophrenia: a rose by any other name? *Schizophrenia Bulletin*, 27, 197–203.
- Phillips, L. R. (2011). Summary of Lessons Learned when working with translators and Interpreters in Reserach. *Journal of Transcultural Nursing*, 22(135), 135-136. doi: 10.1177/1043659610395768
- Pietkiewicz, I., & Smith, J. A. (2014). A practical guide to using Interpretative Phenomenological Analysis in qualitative research psychology. *Psychological Journal*, 20(1), 7-14.
- Pinfold, V. (2001). The Kent awareness-in-action project. Working with the police. Workshop presented at the First International Conference on Reducing Stigma and Discrimination because of Schizophrenia, Leipzig, 3 September.
- Piat, M., Sabatti, J., Couture, A., Sylvestre, J., Provencher, H., Botschner, J. & Stayner, D. (2009). What does Recovery Mean for Me? Perspectives of Canadian Mental Health Consumers. *Psychiatric Rehabilitation Journal*, 32(3), 199-207.
- Pitt, L., Kilbride, M., Nothard, S., Welford, M., & Morrison, A. P. (2007). Researching recovery from psychosis: a user-led project. *The Psychiatric Bulletin*, 31, 55-60. doi: 10.1192/pb.bp.105.008532
- Polit, D. F. & Hungler, B. P. (1999). Nursing research: Principles and methods. 6th edition. Philadelphia: Lippincott.
- Polit, F. D., Beck, T. C., & Hungler, B. P. (2001). *Essentials of Nursing Research Methods, Appraisal, and Utilization*. Philadelphia: Lippincott.
- Ralph, R. O. (2000a). Recovery. *Psychiatric Rehabilitation Skills*, 4(3), 481-517.
- Ralph, R. O. (2000b). *Review of recovery literature: A synthesis of a sample of recovery literature*. Alexandria, VA: National Technical Assistance Centre for State Mental Health Planning (NTAC), National Association for State Mental Health Program Directors (NASMHPD).
- Ralph, R. O. (2000). Review of Recovery Literature: A Synthesis of a sample of Recovery Literature 2000 (pp. 1-35). Southern Maine: National Association of State Mental Health Program Directors.
- Ralph, R. O., Lambert, D. & Kidder., K. A. (2002) *The Recovery Perspective and EvidenceBased Practice for People With Serious Mental Illness: A Guideline Developed for The Behavioural Health Recovery Management project*.  
<http://bhrm.org/guidelines/mhguidelines.htm>
- Recovery Star Research Seminar Report. (2013). Down loaded from: <http://static1.1.sqspcdn.com/static/Report+of+research+seminar+on+Recovery+Star+June+2013>.
- Reeves, S., Kuper, A., & Hodges, B. D. (2008). Qualitative research methodologies: ethnography. *British Medical Journal*, 337, 512-514. doi: 10.1136/bmj.a1020

- Regan, P. (2012). Hans-Georg Gadamer's philosophical hermeneutics; Concepts of reading, understanding and interpretation. *META: Research in Hermeneutics, Phenomenology and Practical Philosophy*, 4 (2), 286-303.
- Regmi, K., Naidoo, J., Pilkington, P. (2010). Understanding the Processes of Translation and Transliteration in Qualitative Research. [Discussion paper]. *International journal of Qualitative Methods*, 9(1), 16-26.
- Reid, K., Flowers, P. and Larkin, M. (2005). Exploring lived experience: an introduction to interpretative phenomenological analysis. *Psychologist*, 18, 20/23.
- Repper, J., & Perkins, R. (2003). *Social Inclusion and Recovery*. London: Bailliere Tindall.
- Rethink. (2005). Recovery learning. A report on the work of the recovery learning sites and other recovery oriented activities and its incorporation in to the rethink plan 200408.[Cited 18 October 2012].
- Reza, A., Breiding, M. J., Gulaid, J., Mercy, J. A., Mthethwa, Z., Bamrah, S., Dahlberg, L.L., Anderson, M. (2009). Sexual violence and its health consequences for female children in Swaziland: a cluster survey study. *Lancet* 373 (1966–72) DOI:10.1016/S0140-6736(09)60247-6
- Richard, W. (2009). Recovery from schizophrenia and the recovery model. [Literature review]. *Current Opinion in Psychiatry*, 22, 374-380.
- Ricoeur, P. (1976). *Paul Ricoeur Interpretation theory: Discourse and the surplus of meaning: Texas*. Texas Christian University Press.
- Ricoeur, P. (1981). *Paul Ricoeur hermeneutics and the human sciences*. (J.B. Thompatientson, Ed.) New York: Cambridge University Press.
- Rice, E. (2006). [Schizophrenia and violence: the perspective of women](#). *Issues in Mental Health Nursing*, 27(9).
- Ridgway, P. (2001). ReStorying psychiatric disability: learning from first person recovery narrative. *Psychiatric Rehabilitation Journal*, 24(3), 335-343.
- Roberts, G. A. (2000). Narrative and severe mental illness: what place do stories have in an evidence-based world?. *Advances in Psychiatric Treatment*, 6(6), 432-441.
- Roberts, G., & Boardman, J. (2013). Understanding 'recovery'. *Advances in psychiatric treatment*, 19(6), 400-409.
- Roberts, G., & Wolfonson, P. (2004). The rediscovery of recovery: open to all. *Advances in Psychiatric Treatment*, 10, 37-49.
- Roberts, G., & Wolfonson, P. (2006). In *Enabling Recovery: The Principles and Practice of Rehabilitation Psychiatry*. Roberts, G., Davenport, S., Holloway, F., & Tattan, T.(eds)., pp. 18-37. Trowbridge: Cromwell Press Limited.
- Roe, D., Mashiach-Eizenberg, M., & Lysaker, P.H. (2011). The relation between objective and subjective domains of recovery among persons with schizophrenia-related disorders. *Schizophrenia Research*, 131, 133-138. doi: 10.1016/j.schres.2011.05.023



- Roger, M.K., Pearson, V., Lam, M., Law C.W., Chiu, C. P.Y., & Chen, E.Y.H. (2008). What does recovery from Schizophrenia mean? Perceptions of long-term patients. *International Journal of Social Psychiatry*, 54(3), 118-130.
- Romano, D. M., McCay, E., Goering, P., Boydell, K., & Zipursky, R. (2010). Reshaping an enduring sense of self: the process of recovery from a first episode of schizophrenia. *Early Intervention in Psychiatry*, 4, 243-250. doi: 10.1111/j.1751-7893.2010.00187.x
- Rose, L., Mallinson, R. K., & Walton-Moss, B. (2002). A grounded theory of families responding to mental illness. *Western Journal of Nursing Research*, 24(5), 516-536.
- Rosler W, Salize HJ, van Os J, Riecher-Rössler A (2005) Size of burden of schizophrenia and psychotic disorders. *Eur Neuropsychopharmacol*. 15(4):399-409
- Rosenham, D. L. (1973). On Being Sane in Insane Places. *Science*, 179:4070, 250-258.
- Rowley, J. & Slack, F. (2004) 'Conducting a literature review'. *Management Research News*, 27(6), pp. 31-39. doi: 10.1108/01409170410784185.
- Rudnick, A. (2008), Recovery from schizophrenia: a philosophical framework. *American Journal of Psychiatric Rehabilitation*. 11, 267-278.
- Ryan, Anne B. (2006) *Post-Positivist Approaches to Research*. In: Researching and Writing your thesis: a guide for postgraduate students. MACE: Maynooth Adult and Community Education, pp. 12-26.
- Saavedra, J., Cubero, M., & Crawford, P. (2009). Incomprehensibility in the narratives of individuals with a diagnosis of schizophrenia. *Qualitative Health Research*, 19(11), 1548-1558.
- Saha, S., Chant, D., Welham, J., & McGrath, J. (2005). A systematic review of the prevalence of schizophrenia. *PLoS Med*, 2(5), e141.
- Sajatovic, M., Jenkins, J. H., Strauss, M. E., Butt, Z. A., Carpenter, E. (2005). Gender Identity and Implications for Recovery Among Men and Women With Schizophrenia. *Psychiatric Services*, 56(1), 96-98.
- Sammel, A. (2003). An Invitation to Dialogue: Gadamer, Hermeneutic Phenomenology and Critical Environmental Education." *Canadian Journal of Environmental Education*, 8:155-68.
- Sandelowski, M. (2000). Focus on Research Methods Whatever Happened to Qualitative Description? *Research in Nursing & Health*, 23, 334-340.
- Sartorius, N., Shapiro, R., Kimura, M., and Barrett, K. (1974). WHO International Pilot Study of Schizophrenia. *Psychological Medicine*, 2, pp 422-425. doi:10.1017/S0033291700045244.
- Saunders Mark, L. P. T. A. (2009). *Research Methods for Business students* (fifth edition ed.). Essex: Pearson Educational Limited.
- Saxena, S., Thornicroft, G., Knapp, M., & Whiteford, H. (2007). Resources for mental health: scarcity, inequity, and inefficiency. *Lancet*, 370(9590), 878-889.

- Sells, D. J., Stayner, D. A., & Davidson, L. (2004). Recovering the self in schizophrenia: An integrative review of qualitative studies. *Psychiatric Quarterly*, 75(1), 87-97.
- Shean, G. D. (2010). *Schizophrenia Etiological models and Evidence based treatments*. New York: Hindawi Publishing Corporation
- Silverman, D. (2003). *Doing Qualitative Research*. London: SAGE Publications.
- Silverman, D. (2004). *Interpreting Qualitative Data Methods for Analysing Talk, Text and Interaction* (2nd ed.). London: SAGE Publications.
- Silverman, D. (2006). *Interpreting Qualitative Data* (3rd ed.). Gosport: Ashford Colour Press Ltd.
- Silverman, D. (2010). *Doing Qualitative Research*. London: SAGE Publication Ltd.
- Silverman, D. (2013). *Doing Qualitative Research* (4<sup>th</sup> Ed). London: SAGE
- Silverstein, S. M., & Bellack, A. S. (2008). A scientific agenda for the concept of recovery as it applies to schizophrenia. *Clinical psychology review*, 28(7), 1108-1124.
- Simmons, O. E. (2006). Some professional and personal notes on research methods, systems theory, and grounded action. *World Futures*, 62(7), 481-490.
- Simms, K. (2003). *Paul Ricoeur*. London: Routledge.
- Singleton, K. D. (Ed.). (2003). *Broken Silence Opening Your Heart and Mind to Therapy*. New York: One World Ballantine Books.
- Slade, M. (2009) 100 Ways to support recovery: a guide for mental health professionals. Rethink Recovery Series
- Smith, J. A. (1996). Beyond the divide between cognition and discourse: Using interpretive phenomenological analysis in health psychology, *Psychology & Health*, 11 (2) 261-271. DOI: 10.1080/08870449608400256
- Smith, M. K. (2000). Recovery from a severe psychiatric disability: Findings of a qualitative study. *Psychiatric Rehabilitation Journal*, 24(3), 149-158.
- Smith, J. A. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology*, 1, 39-54. doi: 10.1191/1478088704qp004oa
- Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research*. Los Angeles: SAGE Publishing Ltd.
- Smith, J. A. (2010). Evaluating the contribution of interpretative phenomenological analysis. *Health Psychology Review*, 5(1), 9-27. doi: 10.1080/17437199.2010.510659
- Smith, J. A. & Osborn, M. (2008). Interpretive phenomenological Analysis. In J.A. Smith (Ed.) *Qualitative Psychology*. London: Sage (2<sup>nd</sup> Ed.)

- Smorti, A., Risaliti, F., Pananti, B., Cipriani, V. (2008). Autobiography as a tool for self-construction: a study of patients with mental disorders. *The Journal of Nervous and Mental. Disease.* 196:531–537.
- Snowden, A. (2009). Classification of schizophrenia. Part one: the enduring existence of madness. *British Journal of Nursing*, 18(19).
- Spaniol L., Wewiorski N., Gagne C. & Anthony W. (2002). The process of recovery from schizophrenia. *International Review of Psychiatry* 14, 327-336.
- Squires, A. (2008). Language barriers and qualitative nursing research: methodological considerations. *International nursing review*, 55(3), 265-273.
- Starks, H., & Trinidad, S. B. (2007). Choose Your Method: A Comparison of Phenomenology, Discourse Analysis. *Qualitative Health Research*, 17(10), 13-721380. doi: 10.1177/1049732307307031
- Stickley, T., & Freshwater, D. (2006). The art of listening in the therapeutic relationship: The role of the modern mental health nurse is becoming more technical when, argue Theodore Stickley and Dawn Freshwater, what would really benefit patients is the often misunderstood art of listening. *Mental health practice*, 9(5), 12-18.
- Streubert, H., & Carpenter, D. R. (Eds.). (2007). *Qualitative Research in Nursing (5th ed.)*. India: Library of Congress-in-Publication data.
- Stuart, H. (2005). Fighting stigma and discrimination is fighting for mental health. *Canadian Policy – Analyse de Politique*, 31, 21-28.
- Sukati, N. A. (1997). Primary health care in Swaziland: is it working. *Journal of Advance Nursing*, 25, 760-766.
- South London & Maudsley NHS Foundation Trust South, West London & St George's Mental Health NHS Trust. (2010). Recovery is for All Hope, Agency and Opportunity in Psychiatry. A Position Statement by Consultant Psychiatrists. Downloaded from: <http://www.rcpsych.ac.uk/pdf/recovery> on 06/02/2014
- Sullivan, W. (1994). 'A long and winding road: the process of recovery form severe mental illness', *Innovations and Research*, 3, 19-27.
- Swanson, K. A., Bastani, R., Rubenstein, L. V., Meredith, L. S., & Ford, D. E. (2007). Effect of mental health care and shared decision making on patient satisfaction in a community sample of patients with depression. *Medical Care Research and Review*, 64(4), 416-430.
- Taylor, J. S., & Bogdan, R. (1984). *Introduction to Qualitative Research Methods (2nd ed.)*. New York: Library of Congress Cataloging in Publication Data.
- Temple, B. & Young, A. (2004). Qualitative Research and Translation Dilemmas. *Qualitative Research*, 4, 161-178. doi: 10:1177/1468794104044430
- Thara, R., Rajkumar, S, & Albert A. J. (2007) Chennai (Madras), India. *In Recovery from Schizophrenia: An International Perspective*. K. Hopper, G. Harrison, A. Janca, and N. Sartorius, eds., pp. 266–276. Oxford: Oxford University Press.

- Thara, R. (2012). Consumer perceptions of recovery: An Indian perspective. *World Psychiatry*, 11(3), 169-170.
- The Schizophrenia Commission. (2012). The abandoned illness: a report from the Schizophrenia Commission. London: Rethink Mental Illness.
- Thornicroft, G., Broham, E., Rose, D., Sartorius, N., Leese, M. (2009). Global pattern of experienced and anticipated discrimination against people with schizophrenia: a cross-sectional survey. *Lancet*, 373: 408–15
- Toner, J. (2000). Schizophrenia: management and care in the community. *British journal of community nursing*, 5(10), 490-493.
- Tooth, B. K. V., Glover, H., & Momenzadah, S. (2003). Factors consumers identify as important to recovery from schizophrenia. *Australian Psychiatry*, 11, 70-77.
- Torgalsboen, A. & Rund, B. R. (2002). Lessons learned from three studies of recovery from schizophrenia. *International Review of Psychiatry*, 14 (4).
- Torgalsboen, A. K., & Rund, B. R. (2010). Maintenance of recovery from schizophrenia at 20-year follow-up: what happened?. *Psychiatry*, 73(1), 70-83.
- Treacy, P. M., & Hyde, A. (Ed.). (1999). *Nursing Research Design & Practice*. Dublin: University College Dublin Press.
- Tsai, J. H.C., Choe, J. H., Lim, J. M. C., Acorda, E., Chan, N. L., Taylor, V., & Tu, S.-P. (2004). Developing culturally competent health knowledge: Issues of data analysis of cross-cultural, cross-language qualitative research. *International Journal of Qualitative Methods*, 3(4), 16-27.
- Tuckett, A. G. (2005). Applying thematic analysis theory to practice: a researcher's experience. *Contemporary Nurse*, 19(1-2), 75-87.
- Turner, A., Barlow, J. and Ilbery, B. (2002). Play hurt, live hurt: Living with and managing osteoarthritis from the perspective of ex-professional footballers. *Journal of Health Psychology*, 7, 285 -301.
- Twin, S. (1997). An exploratory study examining the influence of translation on the validity and reliability of qualitative data in nursing research. *Journal of Advance Nursing*, 26, 418-423.
- Ukpong, D. I., & Abasiubong, F. (2010). Stigmatising attitudes towards the mentally ill: A survey in a Nigerian university teaching hospital. *South African Journal of Psychiatry*, 16(2).
- UNAIDS Gap report, (2014). Global information and advice on HIV & AIDS, HIV and IDS in Swaziland. Retrieved 02 March, 2016 from <http://www.avert.org/professionals/hivaround-world/sub-saharan-africa/swaziland>
- Unzicker, R. (1989). On my own: A personal journey through madness & re-emergence. *Psychosocial Rehabilitation Journal*, 13(1), 71–77.
- Upval, M. J. (1992). Nursing perceptions of collaboration with indigenous healers in Swaziland. *International Journal of Nursing Studies*, 29(1), 27-36.

- van Der Merwe, M., Muir, E., & Cochrane, J., Tziggili, M., & Bowers, L. (2013). Improving seclusion practice: implications of a review of staff and patient views. *Journal of Psychiatric and Mental Health Nursing*, 20 (3), 203-215.
- van Nes, F., Abma, T., & Jonsson, H. (2010). Language differences in qualitative research: is meaning lost in translation? *European Journal of Aging*, 7, 313-316. doi: 10.1007/s10433-010-0168-y
- Warner R. (2004) Recovery from schizophrenia: psychiatry & political economy (3<sup>rd</sup> ed.), London: Routledge & Kegan Paul.
- Warner, R. (2009). Recovery from schizophrenia and the recovery model. *Current opinion in psychiatry*, 22(4), 374-380.
- Warne, T., & McAndrew, S. (2004). The mental health assistant practitioner: an oxymoron?. *Journal of Psychiatric and Mental Health Nursing*, 11(2), 179-184.
- Warne T., & McAndrew S., 2007 Passive Patient or Engaged Expert? Using a Ptolemaic approach to enhance Mental Health Nurse Education and Practice. *International Journal of Mental Health Nursing*, 16 (4) 224 -229
- Warne, T., & McAndrew, S. (2009). Mirror, Mirror: Reflections on Developing the Emotionally Intelligent Practitioner. *Mental Health and Learning Disabilities Research and Practice*, 6(2), 157-167.
- Warne, T., & McAndrew, S. (2010). Re skilled in. *Journal of psychiatric and mental health nursing*, 17(6), 503-509. - searching for
- Watts, G. (2012). Critics attack DSM-5 for overmedicalising normal human behaviour *BMJ* 2012; 344 doi: <http://dx.doi.org/10.1136/bmj.e1020>.
- Waxler, N. E. (1979). Is Outcome for Schizophrenia Better in Nonindustrial Societies?: The Case of Sri Lanka. *The Journal of nervous and mental disease*, 167(3), 144-158.
- Weston, J. M., Norris, V. E., & Clark E. M. (2011). The Invisible Disease: Making Sense of an Osteoporosis Diagnosis in Older Age. *Qualitative Health Research*, 21(12), 1692-1704. doi: 10.1177/1049732311416825
- WHO. (1979). *Schizophrenia: An International Follow up study*. Chichester, UK: John Wiley and Sons.
- WHO. (2001). Nations for mental health Final Report. Downloaded from [www.who.int/mental\\_health/media/en](http://www.who.int/mental_health/media/en) on 23/11/2015
- WHO. (2005). *Swaziland. Mental Health Atlas*.
- WHO. (2009). Mental Health Programmes and Projects. *Geneva, 2009*.
- WHO. (2011). *Swaziland. Mental Health Atlas*. Department of Mental Health and Substance Abuse, World Health Organization.

- Wisdom, J. P., Bruce, K., Saedi, G. A., Weis, T., & Green, C. A. (2008). 'Stealing me from myself': identity and recovery in personal accounts of mental illness. *Australian & New Zealand Journal of Psychiatry*, 42, 489-495.
- Woesner, M.E., Kidd, C. (2012) The Use of Personal Accounts in the Study of Severe Mental Illness. *Innovative medical education*, 40-45.
- Wojnar, M. D., & Swanson, K. M. (2007). Phenomenology An Exploration. *Journal of Holistic Nursing*, 25(3), 172-180. doi: 10.1177/0898010106295172
- Wood, L., Price, J., Morrison, A., & Haddock, G. (2013). Exploring service users perceptions of recovery from psychosis: A Q-methodological approach. *Psychology and Psychotherapy: Theory, Research and Practice*, 86, 245-261. doi: 10.1111/j.20448341.2011.02059.x
- Yardley, L., (2000). Dilemmas in qualitative health research. *Psychology and Health*, 15, 215–228.
- Young, S.L., Ensing, D. S. (1999). Exploring recovery from the perspective of people with psychiatric disabilities. *Psychiatric Rehabilitation Journal*, 22(3), 1-28.
- Zelt, D. (1981). First Person Account; The Messiah Quest. *Schizophrenia Bulletin*, 7(3), 527-531.

# Appendices

- Appendix A** Summary of initial categories of articles
- Appendix B** Swaziland Letter of permission to conduct the study
- Appendix C** Salford Ethics committee
- Appendix D** Participants' information sheet
- Appendix E** Consent form
- Appendix F** OPD Research Information poster
- Appendix G** Letter of invitation
- Appendix H** A summary of Bhoyi's story
- Appendix I** Interview Schedule
- Appendix J** Pholile's story with lines and numbers
- Appendix K** Initial noting and development of themes
- Appendix L** Pholile's Clustered themes
- Appendix M** Pholile's enumerated themes
- Appendix N** Merging to super-ordinate themes
- Appendix O** Further merging to super-ordinate themes
- Appendix P** Summary of participants' stories

## Appendix A: Summary of initial categories of articles

Author	Aim	Methodology	Recruitment/Participants	Data collection	Data analysis	Comments
1. Kalathil et al., 2011	Explore distress & recovery from mental distress from experience of African, African Caribbean and South Asian women.	Reflective Methodology  The research methodology is not explicit.	Researcher living with mental illness 27 women one-to-one interviews, researchers became interviewees (steering group of 7 members)	27 women one-to-one interviews, researchers became interviewees (steering group of 7 members)	Reflective Methodology	
2. Noh et al., 2008	Explore the nature of hope in 25 Koreans with	Qualitative Study	25 Koreans with schizophrenia (16 men & 9 women)		Thematic analysis	
3. Armour, 2009	To examine the lived experience of African-American persons recovering from serious and persistent mental illness	Hermeneutic phenomenological study		Secondary data analysis of the qualitative data collection from an African-America subset (n=9) of all larger sample (n=44)		*Why further explore 9 participants out of 44?
4. McKay, 2010	Explore recovery within the context of the person's everyday life	Narrative inquiry, the life history interview		To explore the experiences of five women living with enduring mental illness in their community	Data was recorded and transcribed verbatim. Data analysis:  -individual unique analysis of each women's life was created	



Author	Aim	Methodology	Recruitment/Participants	Data collection	Data analysis	Comments
					-using the constant comparative analysis.	
5. Borg & Davison, 2008	Explore recovery within the context of the person's everyday life	Qualitative study, using narrative phenomenological methods, based on interviews with individuals in recovery	Seven women and six men were interviewed about their everyday lives and experiences	Seven women and six men were interviewed about their everyday lives and experiences	Thematic and step-wise approach used to analyses the interviews	A comprehensive abstract that clearly delineates the core contents of the research. However, the size of the sample has not been mentioned.
6. Noiseux & Ricard, 2008	Recovery as perceived by people with schizophrenia, family members and health professionals: A grounded theory. To propose a theoretical explanation of recovery based on the concept of human responses put forward by the American Nurses'	Grounded theory		Data were collected from 41 participants: 16 people living with schizophrenia, 5 family members, 20 health professionals	<p>Open coding-underlining significant events, facts and incidents that assist to identify themes</p> <p>*Axial coding-refining open-coding and place a theoretical explanation to each category</p> <p>*Selective coding-integrating and refinement of the theoretical explanation</p>	Further research could be do on finding out the perceptions from each of the three categories (people living with schizophrenia, family members, and health professionals), rather than grouping them together in the discussion. To help compare.

Author	Aim	Methodology	Recruitment/Participants	Data collection	Data analysis	Comments
	Association					
7. Tooth et al., 2003	To identify factors consumers identify as important to recovery from schizophrenia	Four-part qualitative process, consultation with two consumer focus groups	57 people who identified themselves as in recovery were interviewed and tape recorded	Thematic analysis used to identify common themes used by participants	Thematic analysis used to identify common themes used by participants	-Although more men were interviewed in this research, than women, this is said to have no significant on the findings.  -A clearly written research, very similar to the present
8. NG et al., 2008	To investigate the meaning of recovery from patients' perspective in China, Hong Kong	Qualitative methodology based on a three hours focus group	It consisted of four men and four women, and these were randomly selected at the rehabilitation centre which they attend on regular bases	Data was collected from a focus group that was conducted for three hours. It consisted of four men and four women, and these were randomly selected at the rehabilitation centre which they attend on regular bases	Word-for-word transcription of the audio-taped recording was made by the research assistance  The generated data was then analyzed using thematic content analysis approach based on grounded theory. Central thematic framework to describe the data was then used	Well written research paper.  *Issue of language difference is not clearly delineated. For an example what has been done to limit the change of meaning of participants' information during data analysis, were the research assistants English literate?  *What would have been the cause of the hopelessness? In the researchers' discussion of the result this does not come out vive, are these findings or suggestions of what might have caused participants' hopelessness?
9. Lysaker et al., 2010	To explore the issue of whether the quality of a person's personal narrative of his or her life and challenges is a meaningful aspect of recovery from schizophrenia.  *Sought to replicate previous findings linking quantitative assessments of personal narrative with the quality and quantity of an aspect of wellness	Narrative research (Methodology is not explicit). A quantitative study	88 adult men and 15 women with Structured Clinical Interview for the DSM-IV (SCID)	Thematic analysis	Statistical data analysis using three stages.	*This research paper is not clearly written.  The abstract is not summative; it is written as a paragraph, yet it is clearer when the abstract has subheadings of the main points. For an example, the authors would have made it more authentic by indicating the: background, method, results/discussion, and then the conclusion.  *Authors get carried away when discussing the instruments under method. Instead of discussing how the instruments were used in their research, they detailed the general use of each.  *Initials SCID are used earlier in the text, yet explained further down (procedures), confuses the reader

Author	Aim	Methodology	Recruitment/Participants	Data collection	Data analysis	Comments
	(social function)					*Paper is not relevant to my research
10. Spaniol et al., 2002	To identify themes associated with improvement in function and subjective experience	Qualitative Longitudinal		12 individuals with schizophrenia		Similar findings as those of to William, Marilyn Armour and David with Leroy, Wewiorki; the stages of the recovery process.
11. Piat et al., 2009	To explore (for stakeholders receiving, providing or planning mental health services in Canada) the meaning of recovery from the perspectives of consumers receiving mental health services in Canada	Qualitative	54 mental health consumers	<p>In three stages:</p> <ul style="list-style-type: none"> <li>-interviews were coded independently: codes from the questionnaires and others from the data</li> <li>-summaries for each interview was done based on individual themes</li> <li>-summaries were compared and contrasted, and rewritten as a single analytical summary.</li> </ul>	<p><b>In three stages:</b></p> <ul style="list-style-type: none"> <li>-interviews were coded independently: codes from the questionnaires and others from the data</li> <li>-summaries for each interview was done based on individual themes</li> <li>-summaries were compared and contrasted, and rewritten as a single analytical summary.</li> </ul>	<p>A very good research with clearly stated methodology and method of analyzing data.</p> <p>Conclusion: "Thus, conceptualizations of recovery need to account for both definitions it the recovery movement is to represent the view of all consumers."</p>
12. Hoffmann & Kupper, 2002	To identity factors that may facilitate recovery from schizophrenia	Qualitative case study research	-Four out of the 75 participants' interviews were developed into case studies, (looked at in details). These	Four out of the 75 participants' interviews were developed into case studies, (looked at in details). These were selected because they illustrated the varied		<p><b>A significant comment: Due to the varied definition of recovery, as perceived by those living with schizophrenia/mental illness, it is very important for health professionals to ensure that comprehensive services of recovery are made available to all patients.</b></p> <p>-This research did not look at definition of recovery from the patients' perspective, but rather what the researchers found out to promote recovery. In other words it appears as if the researchers made their own conclusion of things that</p>

Author	Aim	Methodology	Recruitment/Participants	Data collection	Data analysis	Comments
			were selected because they illustrated the varied courses taken by individuals in the recovery process.	courses taken by individuals in the recovery process.		promote recovery from schizophrenia, rather than being delineated by participants themselves.
13. Patterson et al., 2011	To examine whether patients' perception of recovery differed for those receiving treatment order (CTO) compared to those who were not	Qualitative study	86 patients		Univariate analysis	There is no stipulation of how participants perceive or define recovery, yet this would provide clear evidence that there is indeed no difference in the perception of recovery between the two groups of participants. In other words, what is the yard stick of measuring that there is no difference in the perception of recovery? Therefore it appears as if this research is not looking at participants' perception of recovery, but is investigating if there is a difference in the perception of recovery between patients on CTOs and those who are not.
14. Ridgway, 2001	To learn important lessons from individual narrative and to determine whether common patterns exist within the lived experience of recovering individuals.	Qualitative study	Four accounts of women who experienced prolonged psychiatric disability and recovered	Four accounts of women who experienced prolonged psychiatric disability and recovered	Thematic analysis,  Constant comparative method: involves identifying and extracting significant statements or meaning units from the narratives.  Mishler's (1986) narrative analytic method used to augment the thematic analysis-helps identify the core narrative (global theme)	-The accounts/narratives were done by a different person from the research, validity of findings compromised, therefore:  -Participants non verbal communication not capture  -some significant information might have not been captured by those who collected the data.
15. Chadwick	To understand recovery in service	A personal Construct Repertory Grid Study	32 adults participated in the		Repertory grid	

Author	Aim	Methodology	Recruitment/Participants	Data collection	Data analysis	Comments
	users with psychosis and		study			
16. Jenkins & Carpenter-Song, 2005	To investigate the experience of recovery from the perspective of people living with schizophrenia-related disorders	Qualitative investigation Ethnographic observation from diverse settings: clinic, public transport, homes, restaurants	90 persons taking second-generation antipsychotic medication		Narrative analysis	<p>A good research paper.</p> <p>Method of data analysis is not vivid; the cultural conundrums (puzzle/confusion) are not clearly discussed. However this is not of significant in this research.</p> <p>-Comment by researchers (Use of medication because participants fear relapse and hospitalization, “this problem complicates the meaning of recovery”): this is not relative, because this is how participants define their own recovery, i.e. recovering/recovered with medication.</p>
17. Bradshaw et al., 2007	Examine the experience of recovery over a period of 3 years	Hermeneutic Phenomenological Study	45 Adults with serious and persistent mental illness (SPMI)		Thematic analysis	<p><b>-Total number of participants is different in the abstract (45) of this paper and when discussing the methods: subjects (44).</b></p> <p><b>Corroborate</b></p> <p><b>-Even though this was a qualitative study, the use of specific figures would have promoted a vivid description of the findings. 20% - only figure mentioned about participants and the relationship with the case manager.</b></p>
18. Smith, 2000	To adduce & enumerate common	Qualitative study	10 people with persistent and		QSR NUD*IST, a software package for qualitative data	Well written paper

Author	Aim	Methodology	Recruitment/Participants	Data collection	Data analysis	Comments
	elements operating among the uniquely personal struggles for recovery from severe psychiatric disability		severe psychiatric disability		analysis, to analyze transcribed interviews	
19. Young & Ensing, 1999	To explore the meaning of recovery process from the perspective of mental health consumers	Qualitative study-grounded theory	7 semi-structured, qualitative interviews and two focus group discussions with 18 people	7 semi-structured, qualitative interviews and two focus group discussions with 18 people	Grounded theory analysis used to identify common, underlying components of the recovery process	
20. Bradshaw et al., 2006	To examine the lived experience of persons recovering from serious and persistent mental illness (SPMI)	Hermeneutic phenomenological study (study of meaning of a text)	Interviews	Interviews were transcribed, read and coded to cluster thematic aspects, Atlas-t used to recode transcripts and retrieve quotes to dimensionalize each essential theme	Interviews were transcribed, read and coded to cluster thematic aspects, Atlas-t used to recode transcripts and retrieve quotes to dimensionalize each essential theme	<p>Positive aspects of this research</p> <ul style="list-style-type: none"> <li>-53% of participants had a diagnosis of schizophrenia</li> <li>-Two consultants used to monitor the influence of subjectivity on the data</li> </ul>



## Appendix B: Swaziland Letter of permission to conduct the study

Telegrams:  
Telex:  
Telephone: (+268 -  
5055170)  
Fax: (+268-5057032)



P.O. BOX 424  
MANZINI  
SWAZILAND

### **NATIONAL PSYCHIATRIC HOSPITAL**

02<sup>nd</sup> August, 2012

MPhil Research Student  
The University of Salford  
The Crescent  
Salford Greater Manchester  
M6 6UP  
United Kingdom

Dear Siphiwe

#### **RE: PERMISSION TO CONDUCT A RESEARCH STUDY**

Permission to undertake a research study on Swazi women living with schizophrenia (perceptions of recovery and their experiences with services provided at the hospital) at the Swaziland National Psychiatric Hospital is granted.

The hospital is grateful that you are conducting this study. The hospital will gain and the findings will be used when providing care to our patients.

We expect you to give the hospital the findings so that the result can be implemented.

Yours faithfully

A handwritten signature in blue ink, appearing to read 'P. Dlamini'.

P.Dlamini  
(Hospital Management)





## Appendix C: Salford Ethics committee



Research, Innovation and Academic  
Engagement Ethical Approval Panel

College of Health & Social Care  
AD 101 Allerton Building  
University of Salford  
M6 6PU

T +44(0)161 295 7016  
r.shuttleworth@salford.ac.uk

[www.salford.ac.uk/](http://www.salford.ac.uk/)

20 July 2012

Dear Siphiwe,

**RE: ETHICS APPLICATION HSCR12/33 – Swazi Women living with schizophrenia: perceptions of recovery in relation to their experiences of the services provided at the Swaziland National Psychiatric Hospital (SNPH)**

Following your responses to the Panel's queries, based on the information you provided, I am pleased to inform you that application HSCR12/33 has now been approved.

If there are any changes to the project and/ or its methodology, please inform the Panel as soon as possible.

Yours sincerely,

*Rachel Shuttleworth*

Rachel Shuttleworth  
College Support Officer (R&I)

***SWAZI WOMEN LIVING WITH SCHIZOPHRENIA: PERCEPTIONS OF RECOVERY IN RELATION TO THEIR EXPERIENCES OF SERVICES PROVIDED AT THE SWAZILAND NATIONAL PSYCHIATRIC HOSPITAL (SNPH). PARTICIPANTS' INFORMATION SHEET (August, 2012).***

## Appendix D: Participants' information sheet

### WHAT IS THIS STUDY ABOUT?

- It is a study taking place at the Swaziland National Psychiatric Hospital, Out Patients' Department (OPD).
- If you are a Swazi women living with schizophrenia the researcher would like to talk to you about your views on recovery and how services in SNPH has helped or could help to promote your recovery.

### WHAT IS THIS STUDY HOPING TO DO?

- To find out what recovery means from the point of view of Swazi women diagnosed with schizophrenia.
- To find out how their experiences of services provided by the SNPH have helped or hindered their recovery.
- To recommend how mental health services at SNPH could help women recover from schizophrenia.

### WHAT WILL HAPPEN DURING THE RESEARCH?

- You will be given information about the research and you can also ask questions.
- Care provided to you will not be affected in any way should you refuse to participate.
- If you are happy to participate you and the researcher can arrange a good time for the interview to take place.
- Before being interviewed you will be asked to sign a consent form. If you wish the form will be explained to you so that you know what you are agreeing to do.
- Once you have signed the form you and the researcher will go to one of the rooms in the OPD where the interview will take place.
- The researcher will provide you with an opportunity to tell your story about what recovery means to you and to share your experiences of services at the SNPH.
- The researcher is interested in what you have to say and hopes that during this process you will feel respected, valued and having dignity.
- You will be free to terminate the interview at any time.

### WHAT NEXT?

- Take the information leaflet and think about participation, contact details are written at the bottom of this sheet if you want more information.
- **Or** inform any member of staff at the OPD if you are ready to participate now.

(Researcher's name) 25054176

(Swazi Nurse's name) at 25058879

Thank you for taking time to listen.

## Appendix E: Consent form

### **CONSENT FORM FOR A RESEARCH ON:**

#### **Swazi women living with schizophrenia: perceptions of recovery in relation to their experiences of the services provided at the Swaziland National Psychiatric Hospital (SNPH)**

***Please tick the appropriate boxes***

**Yes    No**

#### **Taking Part**

I have read the information sheet (dated August 2012), I have been verbally informed about the above research and I understand what I am being asked to do in the project.

☐    ☐

I have been given the opportunity to ask questions about the project, and all questions have been satisfactory answered.

☐    ☐

I agree to take part in the study. Taking part in this study will include being interviewed and this will be audio recorded.

☐    ☐

I understand that my taking part is voluntary; I can withdraw from the study at any time and I do not have to give any reasons for why I no longer want to take part, and that my withdrawal will not affect any aspect of my care.

☐    ☐

☐    ☐

#### **Use of the information I provide for this project only**

I understand my personal details such as my name, phone number and address will not be revealed to people outside this project.

☐    ☐

I understand that my words may be anonymously quoted in publications, reports, web pages, and other research outputs. This means that my name will not be revealed in any report.

☐

\_\_\_\_\_  
Name of participant

[printed]

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Researcher

[printed]

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date



## Appendix F: OPD Information poster

The poster features a white background with a thin black border. At the top, the text "GREATER THINGS ARE YET TO COME!" is written in a rainbow-colored, bold, sans-serif font. Below it, the text "WOMEN ARISE AND SHINE" is also in a rainbow-colored, bold, sans-serif font, with a faint, larger version of the same text visible behind it. Underneath these headlines are five blue rectangular boxes with white text. The first row contains three boxes: "DO YOU WANT TO BE HEARD!", "YOU HAVE THE RIGHT TO CONTRIBUTE TO YOUR CARE", and "HOW DO YOU BEST RECOVER FROM MENTAL ILLNESS?". The second row contains two boxes: "WHAT HAS HELPED, WHAT ELSE CAN" and "MAKE INFORMED DECISIONS, NO PRESSURE". At the bottom, a small line of text provides contact information for the Outpatients' Department (OPD).

**GREATER THINGS ARE YET TO COME!**

**WOMEN ARISE AND SHINE**

**DO YOU WANT  
TO BE HEARD!**

**YOU HAVE THE  
RIGHT TO  
CONTRIBUTE TO  
YOUR CARE**

**HOW DO YOU  
BEST RECOVER  
FROM MENTAL  
ILLNESS?**

**WHAT HAS  
HELPED, WHAT  
ELSE CAN**

**MAKE  
INFORMED  
DECISIONS, NO  
PRESSURE**

LADIES WHO WOULD LIKE TO SHARE THEIR VIEWS, BE LISTENED TO AND IMPROVE CARE PROVIDED AT THIS HOSPITAL CAN OBTAIN MORE INFORMATION ON HOW TO DO THIS AT THE HOSPITAL'S OUT PATIENTS' DEPARTMENT (OPD). Contact Researcher or Nurse at 25054176 (Appendix G)



## Appendix G: Letter of invitation



xxxxxxx  
PhD Research student  
School of Nursing, Midwifery & Social Work  
University of Salford  
Salford, Greater Manchester  
M6 6UP United Kingdom  
Tel: (to be updated)  
Email xxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxx

Date (to be updated)

Dear Madam,

### **Invitation to participate in research study**

My name is xxxxxxxxxxxxxx and I am currently studying for my PhD at the University of Salford, UK. I am writing to invite you to participate in my study.

To be eligible in the study, you must be:

- Female
- Diagnosed with schizophrenia and currently be attending the out-patient department at the SNPH

Your involvement would require you to talk to the researcher in private about what recovery means to you and what services at the SNPH have helped in your recovery and what other services might help more. The interview will last approximately 60 minutes, and will take place in private in a quiet room in the outpatients department of the SNPH. With your permission the interview will be audiotaped.

The university's ethical has been given approval for this study. All information about you collected for this study will be kept confidential, and any identifying information on tape will be removed when the researcher transcribes the tapes.

If you are interested, please feel free to contact xxxxxxx [member of staff] or contact me on my Mobile number xxxxxx and I will provide you with further details of the study.

**Your help would be greatly appreciated**

Yours sincerely

XXXXXXXXXXXXXXXXXXXXXXXXXXXX

## Appendix H: A summary of Bhoyi's story

### **Bhoyi**

My name is Bhoyi. I live about 18 miles away from this hospital. I do want to become better, but I think I am becoming much better now. I do not do the things I did in the past. In the past I would run aimlessly, all over the place, I would even jump over fence. I would go to my work place and swear at my work mates.

When I was admitted in hospital I think the medication helped to make me feel better.

Both my parents died, I am now left with my grandmother. She gives me food and other things that I need. I am able to buy my own clothes because I work in a shop. I am happy about my job and feel good about the fact that I am working. I am now waiting for my sick sheet so that I will be able to take to work and they will pay me for this day, even though I did not go to work. They pay me as long as I bring the sick note to confirm that I was in hospital.

I want to know when I will stop taking these tablets; I have been taking them for a long time now, since 2008.

*Researcher's response: This is a good question; it is worth discussing with the doctor when you see him next. We encourage you to take your medication as prescribed, and prevent stopping treatment abruptly because it could result to a decline in mental state.*



## Appendix I: Interview Schedule

### **INTERVIEW SCHEDULE**

#### **DEMOGRAPHIC DATA:**

Name:.....

Address:.....

Contact Number:.....

Age:.....

Date:.....

Time:.....

(NB. The above will be filled in prior to the interview starting and kept strictly confidential by the researcher only. For the purpose of the research data pseudonyms will be allocated to each participant.)

#### **AREAS OF DISCUSSION DURING NARRATIVE INTERVIEW**

1. What do you understand by the word recovery?
2. What has helped you to feel better while you are admitted at the SNPH?
3. Think about your recovery – what do you think helped your recovery
  - a. At home
  - b. At home
  - c. In the wider community
4. What specific things provide by the SNPH helped your recovery process?
5. What else do you think would have helped your recovery?
  - a. At the SNPH

- b. At home
- c. In the wider community

## **INTERVIEW SCHEDULE**

1. Introduction of the researcher
2. Thank participant for choosing to be involved in the study
3. Provide information about the research, looking at the information sheet and considering ethical issues
4. Give participant opportunity to ask questions
5. Explain the interview process
6. Ask participant to sign the consent form
7. Collect demographic data
8. Ask participant open-ended questions regarding the above
9. Terminate the interview and thank the participants.



## Appendix J: Pholile's story with lines numbers

How do I get lines

## Appendix K: Initial noting and development of themes

Making notes with tracking comments on the side, Heading needs to be out of the box



## Appendix L: Pholile's Clustered themes

### Pholile's Clustered Themes (super-ordinate)

<b>EMERGENT THEMES</b> (subordinate themes)	<b>CLUSTERING</b> (super-ordinate themes) using: <i>abstraction, numeration, subsumption, polarization, function contextualisation</i>	<b>Pinkie's KEY WORDS</b>
<p><i>Family support: knowledgeable and a Christian (1:5,6)</i></p> <p><i>Illness: horrible, terrible, tortured, horrifying experience (1:10-12)</i></p> <p><i>First encounter: came from church (1:10)</i></p> <p><i>Seeing being attacked (1:11)</i></p> <p><i>Insomnia (1:15)</i></p> <p><i>Solicit help at church, benefited (1:16,17)</i></p> <p><i>Second episode: brain confused, came from church, alone (1:19)</i></p> <p><i>Trigger: illness made by prince, causing her to breath as if to take out the spirit(1:21)</i></p> <p>Not confused, ?relieved past experience (1:25)</p> <p>Support through prayer with friends (1:26)</p> <p>Then sent to hospital (2:30)</p> <p><b>Hallucinations:</b></p>	<p><b><i>Chronology of the illness (The horrible the illness)</i></b></p> <p>Illness: horrible, terrible, tortured, horrifying experience (1:10-12)</p> <p>First encounter: came from church (1:10)</p> <p>Seeing being attacked (1:11)</p> <p>Insomnia (1:15)</p> <p>Second episode: brain confused, came from church, alone (1:19)</p> <p>Trigger: illness made by prince, causing her to breath as if to take out the spirit(1:21,22)</p> <p>Visual: people's pictures (2:32)</p> <p>Olfactory: none existing smells (2:33)</p> <p>Tactile: things like demons coming out (2:34)</p> <p>Uncontrollable behaviour: walking, insomnia, became weak</p>	<p>I was terrified, people coming towards me</p> <p>These people were fighting</p> <p>He made me breath like the spirit was coming out</p> <p>See a lot of people's..</p> <p>Smell non existing smells</p> <p>Felt like a lot of things were coming out</p>

<p><i>Visual: people's pictures (2:32)</i></p> <p><i>Olfactory: none existing smells (2:33)</i></p> <p><i>Tactile: things like demons coming out (2:34)</i></p> <p><i>Uncontrollable behaviour: walking, insomnia, became weak (2:35)</i></p> <p><i>Injection: helped to sleep (2:41)</i></p> <p><i>Rough experience of the medication: 'dragging' me (2:43, 44)</i></p> <p><i>Benefits of the injection (2:48)</i></p> <p><i>Listening to nurses (2:49)</i></p> <p><i>Nurses' conditional love: listen/obedient (2:51)</i></p> <p><i>Seclusion: Lonely, (2:56)</i></p> <p><i>Little help: spirit left me (2:57); to get better (3:68)</i></p> <p><i>Seclusion: compulsory on admission (3:67, 72)</i></p> <p><i>Not nice, disliked (3:60)</i></p> <p><i>A prison, encaged (3:62)</i></p> <p><i>Compulsory on admission (3:72)</i></p> <p><i>Discharge from seclusion based on client's will to comply (listen) (3:71,72,74)</i></p> <p><i>Medication beneficial, if well taken (3:75)</i></p> <p><i>Nurse's love: re-enforces: allow family bond (3:80, 81)</i></p> <p><i>Nurse: acceptance, not stigmatise me (3:82)</i></p>	<p>(2:35)</p> <p>Injection: helped to sleep (2:41)</p> <p><b><i>Rough experience from medication and the illness (Dragged)</i></b></p> <p>Rough experience of the medication: 'dragging' me (2:43, 44)</p> <p>Benefits of the injection (2:48)</p> <p>Side effects of medication error: labelled as ill, no one interested in listening (5:118)</p> <p>Injection deprives ones' liberty, becoming unproductive (5:130,131)</p> <p>Injection a hindrance: physically, emotional and life progress (12:324,325)</p> <p>Rest not helpful, feels worthless, not industrious/ energetic (8:223)</p> <p>A desire for change: reiterated bad treatment when not ill (10:287-288)</p> <p>Chemical restrained: injected (10:288)</p> <p>Irreversible effects: dragged on the floor, life time pain, was normal before (11:289)</p> <p>Retarded progress: bible college and marriage: no money (9:256, 257)</p> <p>Coerced treatment: the pain that never dies (11:304)</p>	<p>Walking the whole night, I could not stop</p> <p>They gave me an injection, then I slept</p> <p>Felt like I was dragged, they just dragged me</p> <p>Injection helped me</p> <p>I confused the medication....became very sleep</p> <p>Given an injection....not ill..injection made me sleepy</p> <p>This injection wasted my time because it made me feel like I was dragged</p> <p>I just sit and rest for a moment, I am useless, but ask for support</p> <p>I am looking at this thing that happened to me, it really hurt</p> <p>That I was given an injection when I was well</p> <p>This injection hurts your life, you find yourself being dragged on the floor</p> <p>I need money for my wedding...have the gift of marriage and preaching</p> <p>But the injection just kills you</p> <p>Injection made me swell, I</p>
--	---	---

<p><i>Nurses: Reprimand to guide you, as one does to a child (3:85)</i></p> <p><i>Hospitalisation: return to normal, become productive, excel (3:87)</i></p> <p><i>Recovery with medication, identify with others, back at work (4:89-91)</i></p> <p><i>Recovery: perseverance: (4:92)</i></p> <p><i>Fulfilment of a unique need: visits from significant others and universality (4:97-103)</i></p> <p><i>Fulfilment of need for visitors emphasised, medication, food not a substitute (4:97-103)</i></p> <p>Home food boring, no variety, self admission requested (4:105,110)</p> <p><i>Voluntary admission for food, makes you better (4:112)</i></p> <p><b>? Situation/verbal Irony? Flight of ideas? Sudden change of subject (4:112)</b></p> <p><i>Stigmatised: mentally ill because of different beliefs (5:117)</i></p> <p><i>Side effects of medication error, labelled as ill, no one interested in listening (5:118)</i></p> <p><i>Accused of insomnia (5:125)</i></p> <p><i>Professionals' stigmatisation (5:126, 127)</i></p> <p><i>Injection deprives ones' liberty, becoming unproductive (5:130,131)</i></p> <p>Misunderstood: excitement or illness (5:134)</p> <p><i>Labelled with mental illness because of hatred (5:138)</i></p> <p><i>Ridiculed and mocked by a neighbour (5:140, 141)</i></p>	<p>Body disfigured by injection, loss of self confidence, esteem (11:307)</p> <p><b><i>Seclusion is like a prison (Ekhulukutfu kubuhlungu)</i></b></p> <p>Seclusion: Lonely, (2:56)</p> <p>Little help: spirit left me (2:57); to get better (3:68)</p> <p>Seclusion: compulsory on admission (3:67, 72)</p> <p>Not nice, disliked (3:60)</p> <p>A prison, encaged (3:62)</p> <p><b><i>Care and support form family, community and church (Support: community)</i></b></p> <p>Family support: knowledgeable and a Christian (1:5,6)</p> <p>Solicit help at church, benefited (1:16,17)</p> <p>Fulfilment of a unique need: visits from significant others and universality (4:97-103)</p> <p><b><i>Hospital stuff's love and support (Support: hospital)</i></b></p> <p>Nurses' conditional love: listen/obedient (2:51)</p> <p>Nurse's love: re-enforces: allow family bond (3:80, 81)</p> <p>Nurse: acceptance, not stigmatise me (3:82)</p>	<p>became fat</p> <p>Seclusion is a place where you stay alone</p> <p>Yes the spirit go out</p> <p>I just arrived isn't it, I was admitted</p> <p>Seclusion is not nice, nobody likes seclusion</p> <p>It makes you feel like you are in prison</p> <p>Found that my small grandmother is educated..used to hospitals</p> <p>Illness was a little better after prayer</p> <p>Feel better..when others have visitors and you don't...</p> <p>Nurse had love, especially when you listen</p> <p>Bring your parent in, let her come to visit</p> <p>They take you like a person who is well</p> <p>You go back to become like a child</p> <p>I was a leader at the score</p>
--	--	---



<p><i>Half brother causing conflicts, influenced by weed (5:143)</i></p> <p>Chased from home by half brother, lived with uncle (6:145)</p> <p><i>Conflicts/stigmatised at uncle: sorting and burning old cloths: labelled mad (6:150)</i></p> <p><i>Her children abused by lady, stopped from attending school (6:152)</i></p> <p><i>Stressful life: being bullied, emotional abuse (6:155-158)</i></p> <p><i>Labelled: mad women spreading to the whole neighbourhood (6:156)</i></p> <p><i>Continually infuriate, disturbed mind, no peace within: defended herself (6:160-163)</i></p> <p><i>Spoke with the doctor, not heard, restrained and injected (6:166-168)</i></p> <p><i>Stigmatised: coerced, mistreated, misinterpreted, misunderstood, misjudged (6:168-170)</i></p> <p><i>Mistreated, helpless: fighting back by calling pastor (6:170)</i></p> <p><i>Coerced treatment, side effect weight gain (7:174,175)</i></p> <p><i>Exasperated by lady's emotional abuse, developed physical symptoms (7:178-180)</i></p> <p>Recovery associated with emotionally stable (7:186)</p> <p>Not employed advantageous, less stress, can sleep, misunderstood by step mother (7:187)</p> <p><i>Step mother: not supportive responsible for financial abuse (7:188)</i></p> <p><i>Step-mother tortured me and abused my children (7:191-197)</i></p> <p><i>Financial difficult, step mother's financial abuse a contribution</i></p>	<p>Nurses: Reprimand to guide you, as one does to a child (3:85)</p> <p>Hospitalisation: return to normal, become productive, excel (3:87)</p> <p>Recovery with medication, identify with others, back at work (4:89-91)</p> <p>Voluntary admission for food, makes you better (4:110)</p> <p><b><i>God with me, it will be okay (Support: above)</i></b></p> <p>Spirituality: trust in the supernatural to help (8:204)</p> <p>Final support received through offering from others (8:205, 208)</p> <p>Surrendered problems to God: (8:229)</p> <p>Looked for solution, prove fruitless, files missing in court (9:238)</p> <p>Trust God's intervention (9:236)</p> <p>Trust in God brings home, coping strategy, helps to persevere (10:267-269)</p> <p>Hopes that things will be sorted at the right time (10:270,271)</p> <p>Have confidence in God and church due to previous provision (10:275-279)</p> <p>Strongly belief in God for future success (10:282)</p> <p>Coping strategies: reassured by God's revelation about the lady (9:251)</p>	<p>At the firm where I used to work..you go back to normal</p> <p>You really become well with this medication</p> <p>Told the doctor no, I want to stay here.</p> <p>I have asked God's servant and the church to pray for me</p> <p>..ask for others to help me..go to town to ask for support</p> <p>I am looking unto the King to help me</p> <p>Told..no files..this book with that one..this book was with that one</p> <p>God helped me there</p> <p>He will open a way, he is faithful</p> <p>...lots of support from the church</p> <p>Yes if you trust God he will open for you big opportunities</p> <p>There is so much conflict now</p> <p>Yet because I believe in God, I do pray, he helps you when you</p>
---	--	---

<p>(7:199-200)</p> <p><i>No strength/ motivation to work contribute to financial difficult (7:201,202 )</i></p> <p><i>Spirituality: trust in the supernatural to help (8:203)</i></p> <p><i>Finical support received through offering from others (8:205, 208)</i></p> <p><i>The pain of seeing one's children being abused (8:213,214 )</i></p> <p><i>Rest not helpful, feels worthless, not industrious/ energetic (8:223)</i></p> <p>Step mother: financial abuser, non empathetic (8:226-228)</p> <p><i>Surrendered problems to God: (8:229)</i></p> <p><i>Looked for solution, prove fruitless, files missing in court (9:238)</i></p> <p><i>Trust God's intervention (9:236)</i></p> <p><i>Conflicts with half siblings (9:240)</i></p> <p><i>Ridiculed, mocked &amp; insulted by siblings (9:242-246)</i></p> <p><i>Evil from half siblings is contagious, physical effects (9:246-249 )</i></p> <p><i>Coping strategies: reassured by God's revelation about the lady (9:251)</i></p> <p><i>Difficult circumstance: (9:256-286 )</i></p> <p><i>Retarded progress: bible college and marriage: no money (9:256, 257)</i></p> <p>Perpetual family conflicts, no progress (9:258; 10:260-264)</p> <p><i>Trust in God brings home, coping strategy, helps to persevere (10:267-269)</i></p>	<p>Difficult circumstance: (9:256-258)</p> <p>Trust in God for help (11:302)</p> <p><b><i>I must be willing to work with the nurses (Up to me)</i></b></p> <p>Listening to nurses (2:49)</p> <p>Discharge from seclusion based on client's willingness to comply (listen) (3:71,72,74)</p> <p>Medication beneficial, if well taken (3:75)</p> <p>Recovery: perseverance: (4:92)</p> <p>No strength/ motivation to work contribute to financial difficult (7:201,202 )</p> <p><b><i>That mad women: ridiculed for living with the illness (She is mad, don't worry?)</i></b></p> <p><b><i>I can talk for myself, only listen?</i></b></p> <p><b><i>I am not mad, only listen (stigma+listen)</i></b></p> <p>Accused of not sleeping (5:125)</p> <p>Stigmatised: mentally ill because of different beliefs (5:117)</p> <p>Labelled with mental illness because of hatred (5:138)</p> <p>Ridiculed and mocked by a neighbour (5:140, 141)</p> <p>Half brother causing conflicts, influenced by weed (5:143)</p> <p>Conflicts/stigmatised at uncle: sorting and burning old cloths:</p>	<p>are in need</p> <p>I listened to what the nurses were saying</p> <p>You stay there until you can listen</p> <p>The medication is good, it help you a lot, if you drink it well you become better</p> <p>You get home..feel pressured</p> <p>No getting up to go to the boss..I do not have that strength within me</p> <p>.....they told lies about me...said I was not sleeping</p> <p>...he told people that I did not sleep</p> <p>In this area one of the people did not like me</p> <p>Lady left her house..came to mine...caused trouble</p> <p>It was not until one of my half brothers started causing trouble</p> <p>She started telling everybody that she sis mad, she is mad</p> <p>She would force my child to stay home and do chores...I realised that she did not go to</p>
---	---	--

<p><i>Hopes that things will be sorted at the right time (10:270,271)</i></p> <p><i>Have confidence in God and church due to previous provision (10:275-279)</i></p> <p><i>Strongly belief in God for future success (10:282)</i></p> <p><i>A desire for change: reiterated back treatment when not ill (10:287-288)</i></p> <p><i>Chemical restrained: injected (10:288)</i></p> <p><i>Irreversible effects: dragged on the floor, life time pain, was normal before (11:289)</i></p> <p><i>Talked to nurse, not heard (11:298)</i></p> <p>Self defence, being assertive, labelled as abnormal behaviour (11:299)</p> <p><i>Trust in God for help (11:302)</i></p> <p><i>Coerced treatment: the pain that never dies (11:304)</i></p> <p><i>Staff listened to me in the past when I had come to ask for food. Why did they not listen to me this time (11:305, 306)</i></p> <p><i>OR</i></p> <p><i>Do they not recognise that I am the same lady who use to ask for food and went back home (11:305, 306)</i></p> <p><i>Body disfigured by injection, loss of self confidence, esteem (11:307)</i></p>	<p>labelled mad (6:150)</p> <p>Her children abused by lady, stopped from attending school (6:152)</p> <p>Stressful life: being bullied, emotional abuse (6:155-158)</p> <p>The pain of seeing one's children being abused (8:213,214 )</p> <p>Labelled: mad women spreading to the whole neighbourhood (6:156)</p> <p>Continually infuriate, disturbed mind, no peace within: defended herself (6:160-163)</p> <p>Spoke with the doctor, not heard, restrained and injected (6:166-168 )</p> <p>Stigmatised: coerced, mistreated, misinterpreted, misunderstood, misjudged (6:168-170)</p> <p>Mistreated, helpless: fighting back by calling pastor (6:170)</p> <p>Coerced treatment, side effect weight gain (7:174,175)</p> <p>Exasperated by lady's emotional abuse, developed physical symptoms (7:178-180)</p> <p>Step mother: not supportive responsible for financial abuse (7:188)</p> <p>Step-mother tortured me and abused my children (7:191-197)</p> <p>Financial difficult, step mother's financial abuse a contribution (7:199-200)</p> <p>Professionals' stigmatisation (5:126, 127)</p>	<p>school</p> <p>She would insult me and insult me....shout on the other side saying this mad lad, this mad lady</p> <p>I was then called a mad person</p> <p>She never stopped, she provoked me and provoked me</p> <p>They continued to hold me and injected me, I did tell the doctor</p> <p>I felt I should phone my pastor and report that they took me to hospital even though I was not ill</p> <p>I us to suffer from headaches because this lady would talk a lot and she would insult me a lot</p> <p>The step mother does not support you...she tortured my children</p> <p>My life is difficult...have no money...yet money is being withheld by the step mother</p> <p>The doctor did not speak much, all he knows is that this is a patient, she is mad</p>
---	---	---

<p><i>A plea for staff to pause and listen to patients at all times (11:313)</i></p> <p><i>Found others in hospital who were wrongly admitted: pastor (11:314-316)</i></p> <p><i>A wish that other would not go through the same experience, its damaging (12:318, 319)</i></p> <p><i>Injection a hindrance: physically, emotional and life progress (12:324,325)</i></p> <p><i>Promised financial support at the hospital, did not materialise (12:334-336)</i></p>	<p>Conflicts with half siblings (9:240)</p> <p>Ridiculed, mocked &amp; insulted by siblings (9:242-246)</p> <p>Evil from half siblings is contagious, physical effects (9:246-249 )</p> <p>Talked to nurse, not heard (11:298)</p> <p>Staff listened to me in the past when I had come to ask for food. Why did they not listen to me this time (11:305, 306)</p> <p>OR</p> <p>Do they not recognise that I am the same lady who use to ask for food and went back home (11:305, 306)</p> <p>Others taking control over me as if they know me better than I do (12:321)</p> <p>A plea for staff to pause and listen to patients at all times (11:313)</p> <p>Found others in hospital who were wrongly admitted: pastor (11:314-316)</p> <p>A wish that others would not go through the same experience, its damaging (12:318, 319)</p> <p>Promised financial support at the hospital, did not materialise</p>	<p>I did tell the nurse....giving me the injection....because I was talking too much to defend myself....I think she said she is shouting...needs the injection</p> <p>I us to come to the hospital tell them that I was not okay...I needed food...gave me food..went back home</p> <p>I know myself, I know my illness..know importance of taking medication..don't want to die...I have my children</p> <p>I want the staff at the hospital to listen to patients, not to inject them without listening</p> <p>I met a pastor...said I was stood at the bus rank holding mu bible...police took me..said..told by this person that you are not okay</p> <p>..my wish that this would not happen again</p>
--	--	--

	(12:334-336)	...we did not get the money
--	--------------	-----------------------------

## Appendix M: Pholile's enumerated themes

### **Pholile's emergent themes**

Family support: knowledgeable and a Christian (1:5,6)

Illness: horrible, terrible, tortured, horrifying experience (1:10-12)

First encounter: came from church (1:10)

Seeing being attacked (1:11)

Insomnia (1:15)

Solicit help at church, benefited 10/12

Second episode: brain confused, came from church, alone (1:19)

Trigger: illness made by prince, causing her to breath as if to take out the spirit(1:21)

Not confused, ?relieved past experience (1:25)

Support through prayer with friends  
(1:26)

Then sent to hospital (2:30)

### **Hallucinations:**

Visual: people's pictures (2:32)

Olfactory: none existing smells (2:33)

Tactile: things like demons coming out  
(2:34)

Uncontrollable behaviour: walking, insomnia, became weak (2:35)

Injection: helped to sleep (2:41)

Rough experience of the medication: 'dragging' me (2:43, 44)

Benefits of the injection (2:48)

Listening to nurses (2:49)

Nurses' conditional love: listen/obedient (2:51)

Seclusion: Lonely, (2:56)

Little help: spirit left me (2:57); to get better (3:68)

Compulsory on admission (3:67, 72)

Not nice, disliked (3:60)

A prison, encaged (3:62)

Compulsory on admission (3:72)

Discharge from seclusion based on client's will to comply (listen) (3:71,72,74)

Medication beneficial, if well taken

Nurse's love: re-enforces: allow family bond (3:80, 81)

Nurse: acceptance, not stigmatise me (3:82)

Nurses: Reprimand to guide you, as one does to a child (3:85)

Hospitalisation: return to normal, become productive, excel (3:87)

Recovery with medication, identify with others, back at work (4:89-91)

Recovery: perseverance: (4:92)

Fulfilment of a unique need: visits from significant others and universality (4:97-103)

Fulfilment of need for visitors emphasised, medication, food not a substitute (4:97-103)

Home food boring, no variety, self admission requested (4:105,110)

Voluntary admission for food, makes you better (4:112)

**?Situation/verbal Irony? Flight of ideas? Sudden change of subject (4:112)**

Stigmatised: mentally ill because of different beliefs

Side effects of medication error, labelled as ill, no one interested in listening (5:118)

Accused of insomnia (5:125)

Professionals' stigmatisation (5:126, 127)

Injection deprives ones' liberty, becoming unproductive (5:130,131)

Misunderstood: excitement or illness (5:134)

Labelled with mental illness because of hatred (5:138)

Ridiculed and mocked by a neighbour (5:140, 141)

Half brother causing conflicts, influenced by weed (5:143)

Chased from home by half brother, lived with uncle (6:145)

Conflicts/stigmatised at uncle: sorting and burning old cloths: labelled mad (6:150)

Her children abused by lady, stopped from attending school (6:152)

Stressful life: being bullied, emotional abuse (6:155-158)

Labelled: mad women spreading to the whole neighbourhood (6:156)

Continually infuriate, disturbed mind, no peace within: defended herself (6:160-163)

Spoke with the doctor, not heard, restrained and injected (6:166-168 )

Stigmatised: coerced, mistreated, misinterpreted, misunderstood, misjudged (6:168-170)

Mistreated, helpless: fighting back by calling pastor (6:170)

Coerced treatment, side effect weight gain (7:174,175)

Exasperated by lady's emotional abuse, developed physical symptoms (7:178-180)

Recovery associated with emotionally stable (7:186)

Not employed advantageous, less stress, can sleep, misunderstood by step mother (7:187)

Step mother: not supportive responsible for financial abuse (7:188)

Step-mother tortured me and abused my children (7:191-197)

Financial difficult, step mother's financial abuse a contribution (7:199-200)

No strength/ motivation to work contribute to financial difficult (7:201,202 )

Spirituality: trust in the supernatural to help (8:203)

Finical support received through offering from others (8:205, 208)

The pain of seeing one's children being abused (8:213,214 )

Rest not helpful, appears to feel worthless, not industrious/ energetic (8:223)

Step mother: financial abuser, non empathetic (8:226-228)

Surrendered problems to God: (8:229)

Looked for solution, prove fruitless, files missing in court (9:238)

Trust God's intervention (9:236)



Conflicts with half siblings (9:240)

Ridiculed, mocked & insulted by siblings (9:242-246)

Evil from half siblings is contagious, physical effects (9:246-249 )

Coping strategies: reassured by God's revelation about the lady (9:251)

Difficult circumstance: (9:256-286 )

Retarded progress: bible college and marriage: no money (9:256, 257)

Perpetual family conflicts, no progress (9:258; 10:260-264)

Trust in God brings home, coping strategy, helps to persevere (10:267-269)

Hopes that things will be sorted at the right time (10:270,271)

Have confidence in God and church due to previous provision (10:275-279)

Strongly belief in God for future success (10:282)

A desire for change: reiterated back treatment when not ill (10:287-288)

Chemical restrained: injected (10:288)

Irreversible effects: dragged on the floor, life time pain, was normal before (11:289)

Talked to nurse, not heard (11:298)

Self defence, being assertive, labelled as abnormal behaviour (11:299)

Trust in God for help (11:302)

Coerced treatment: the pain that never dies (11:304)

Staff listened to me in the past when I had come to ask for food. Why did they not listen to me this time (11:305, 306)

OR

Do they not recognise that I am the same lady who use to ask for food and went back home (11:305, 306)

Body disfigured by injection, loss of self confidence, esteem (11:307)

A plea for staff to pause and listen to patients at all times (11:313)

Found others in hospital who were wrongly admitted: pastor (11:314-316)

A wish that other would not go through the same experience, its damaging (12:318, 319)

Injection a hindrance: physically, emotional and life progress (12:324,325)

Promised financial support at the hospital, did not materialise (12:334-336)

## Appendix N: Merging to super-ordinated themes

### Bringing them all together

*How the sub-ordinate themes were merged into super ordinate 1.*

#### 1. The terror/illness of the brain

- Chronology of the illness, **Polile**
- Being dragged, medication, **Polile**
- I was not who I am because of the illness, **Welile**
- How it started, **Polile**
- Illness: the thing that tortures the body and brain, **Salaphi**
- The restrictions of the illness: behaviour, thoughts mood and others, **Winile**
- Potential limiting illness: voices, fear, **Thobile**
- Illness started with disturbance of my spirit, **Nono**
- Talking with invisible people, **Selina**
- Injury to the brain, **Tholu**
- Risk to others, **Tenele**
- My brain was hurt, **Felaphi**
- Uncontrollable, dehumanising behaviour, **Eli**
- Illness changed me, **Lulu**
- Problems, problems, problems make me crazy, **Jojo**
- The mental pain of being financially crippled, **Jojo**

#### 2. Spirituality

- God my comfort
- God with me, it will be okay, **Polile**
- At church benefit from giving and receiving, **Nono**
- Prayer did not help me, **Winile**
- I do go to church, not getting much there, **Selina**
- Praying makes me feel well in the brain, **Eli**

#### 3. Kubancono (Being better)

- Attending church is therapeutic, **Welile**
- At least I can look back and be happy, **Felaphi**
- Family support, attention to basic needs, **Tenele**
- Living with the illness and being HIV positive is not easy, **Selina**
- Acceptance of what I cannot change, focus on my desire: determined to be discharged from hospital, **Tholu**
- When I am better: use of hobby, community involvement, **Selina**
- It's up to me, I must be willing to work with nurses, **Polile**
- Benefits from medication and family support, **Selina**
- It's up to me: my choice to comply, **Winile**
- I am responsible for where I want to be, **Tholu**
- Medication can be good or bad, **Thobile**

- Being better; family support, harmony, love, balancing work and rest, **Nono**
- It's up to me: determined to be productive, **Thobile**
- Being in control: I know me best not you, **Salaphi**
- Being productive, occupied helps become better, **Lulu**
- A sense of hope at the end of the tunnel, **Eli**
- Difficult rule of medicine, better flexibility of traditional medicine, **Winile**
- Taking medication out of fear, **Eli**
- Being better, indicators: self care, respect, **Eli**
- Taking medication because the doctor said so, **Welile**
- Being better is not possible, **Londi**
- Benefited from going to church: power of fellowship, **Lulu**
- I can chose whether to be admitted or not: home is best, **Welile**
- I know when I need hospital admission, **Nono**
- Hopelessness, **Jojo**

#### 4. Who will help me?

- Interruption to being better: imposed treatment, **Salaphi**
- Fulfil a need
- Dreadfully treated by hospital staff: bitten, bad language, **Welile**

- I will not be admitted in hospital again. Traditional healers are the same (beaten there too), **Winile**
- Beaten by hospital staff, , **Tenele**

#### 5. Buhlungu bekhulukutfu!

- You are destroyed in seclusion: thrown in, **Winile**
- I did not deserve being sent put in seclusion, **Salaphi**
- Poisoned with medication, **Salaphi**
- Seclusion too small, could suffocate, **Selina**
- Dignity lost in seclusion, **Welile**

#### 6. Some of them are better.

- Hospital medication, injection helped to become better, **Winile**
- Hospital holistic care: education support, food, therapeutic environment, **Salaphi**
- Hospital care average, staff not excellent: health education from students on placement, **Welile**
- Empowered by hospital staff: regained lost social skills, **Thobile**
- Talking with staff helped, **Nono**
- Good care from hospital staff, **Selina**
- Medication is not the answer, **Jojo**
- Hospital staff did less, **Selina**
- Engaging in therapeutic activities, a therapeutic distraction, **Tholu**
- Hospital care changed for better, **Felaphi**

#### 7. Luhlanya lolu.....

- My child and I dumped by the father, **Selina**
- That mad women, ridiculed for living with the illness of the brain, **Polile**
- Living with the illness and socio-cultural dynamics, **Salaphi**
- Being put down by those in power: husband, police, professionals, **Salaphi**
- Unplanned hospital admission – dumped: relatives and hospital staff, **Nono**
- Wanting to fit in: pauses high risk of relapse, **Welile**
- Not accepted by everybody, **Winile**
- Return to work delayed, restrictions not acceptable, **Thobile**
- Disadvantaged because I live with the illness: land and job taken away from me, **Eli**
- Self confidence: I refused to go to seclusion for no reason, **Tenele**
- Stigmatised, **Jojo**

#### 8. Being fulfilled/ability to overcome

- Peace with others, **Felaphi**
- I am better than those that don't accept me, **Felaphi**
- Something good comes out of this illness, **Salaphi**
- I have a dream to generate income, **Selina**
- I am not as bad as others think I am, I have accomplished a lot, **Thobile**

- The war within me, **Thobile**
- Desire to overcome, **Welile**
- The joy of being included, **Winile**
- Determination to rise above constraints, **Winile**
- The joy of being valued by others, **Tholu**
- Motivated to win: hobby used productively, set goals, refused seclusion (to be put down by others) , **Tenele**
- Working hard, making goals, learning new things, **Eli**

## Appendix O: Further merging to super-ordinate themes

Together 2

### Bringing them all together 2

*How the sub-ordinate themes were merged into super ordinate, stage two.*

#### 1. The terror/illness of the brain (Experience of living with schizophrenia)

##### 1.1The illness defined

- Brian hurt, injury to the brain,
- My brain was hurt, **Felaphi**
- Injury to the brain, **Tholu**
- Illness started with disturbance of my spirit, **Nono**
- How it started, **Polile**
- Chronology of the illness, **Polile**
- The mental pain of being financially crippled, **Jojo**
- Problems, problems, problems make me crazy, **Jojo**

##### 1.2The changed self

- Uncontrollable,
- dehumanising behaviour, risk to others
- Risk to others, **Tenele**
- I was not who I am because of the illness, **Welile**
- The restrictions of the illness: behaviour, thoughts mood and others, **Winile**

##### 1.3The illness tortures

- the body and brain,

- limiting, restricting: behaviour, mood, Conflicts within
- Illness changed me, **Lulu**
- Talking with invisible people, **Selina**
- Potential limiting illness: voices, fear, **Thobile**
- Illness: the thing that tortures the body and brain, **Salaphi**
- Being dragged, medication, **Polile**

## 2. Kubancono (Being better) (what does it mean to me to be better, makes me say I am better or not, evidence, indications, I am better when...)

- God my comfort
- God with me, it will be okay, **Polile**
- At church benefit from giving and receiving, **Nono**
- Prayer did not help me, **Winile**
- I do go to church, not getting much there, **Selina**
- Praying makes me feel well in the brain, **Eli**
- Attending church is therapeutic, **Welile**
- At least I can look back and be happy, **Felaphi**
- Family support, attention to basic needs, **Tenele**
- Living with the illness and being HIV positive is not easy, **Selina**
- Acceptance of what I cannot change, focus on my desire: determined to be discharged from hospital, **Tholu**
- When I am better: use of hobby, community involvement, **Selina**
- It's up to me, I must be willing to work with nurses, **Polile**
- Benefits from medication and family support, **Selina**
- It's up to me: my choice to comply, **Winile**
- I am responsible for where I want to be, **Tholu**

- Medication can be good or bad, **Thobile**
- Being better; family support, harmony, love, balancing work and rest, **Nono**
- It's up to me: determined to be productive, **Thobile**
- Being in control: I know me best not you, **Salaphi**
- Being productive, occupied helps become better, **Lulu**
- A sense of hope at the end of the tunnel, **Eli**
- Difficult rule of medicine, better flexibility of traditional medicine, **Winile**
- Taking medication out of fear, **Eli**
- Being better, indicators: self care, respect, **Eli**
- Taking medication because the doctor said so, **Welile**
- Being better is not possible, **Londi**
- Benefited from going to church: power of fellowship, **Lulu**
- I can chose whether to be admitted or not: home is best, **Welile**
- I know when I need hospital admission, **Nono**
- Hopelessness, **Jojo**
- **Some of them are better.**
- Hospital medication, injection helped to become better, **Winile**
- Hospital holistic care: education support, food, therapeutic environment, **Salaphi**
- Hospital care average, staff not excellent: health education from students on placement, **Welile**
- Empowered by hospital staff: regained lost social skills, **Thobile**
- Talking with staff helped, **Nono**
- Good care from hospital staff, **Selina**
- Medication is not the answer, **Jojo**
- Hospital staff did less, **Selina**

- Engaging in therapeutic activities, a therapeutic distraction, **Tholu**
- Hospital care changed for better, **Felaphi**

### **3. Violation of rights (hindrances of recovery)**

#### **Buhlungu bekhulukutfu! (The pain of seclusion)**

- Interruption to being better: imposed treatment, **Salaphi**
- Dreadfully treated by hospital staff: bitten, bad language, **Welile**
- I will not be admitted in hospital again. Traditional healers are the same (beaten there too), **Winile**
- Beaten by hospital staff, , **Tenele**
- You are destroyed in seclusion: thrown in, **Winile**
- I did not deserve being sent put in seclusion, **Salaphi**
- Poisoned with medication, **Salaphi**
- Seclusion too small, could suffocate, **Selina**
- Dignity lost in seclusion, **Welile**

### **4. Tarnish (a standalone hindrance to recovery)**

- My child and I dumped by the father, **Selina**
- That mad women, ridiculed for living with the illness of the brain, **Polile**
- Living with the illness and socio-cultural dynamics, **Salaphi**
- Being put down by those in power: husband, police, professionals, **Salaphi**
- Unplanned hospital admission – dumped: relatives and hospital staff, **Nono**
- Wanting to fit in: pauses high risk of relapse, **Welile**
- Not accepted by everybody, **Winile**
- Return to work delayed, restrictions not acceptable, **Thobile**
- Disadvantaged because I live with the illness: land and job taken away from me, **Eli**



- Self confidence: I refused to go to seclusion for no reason, **Tenele**
- Stigmatised, **Jojo**

##### **5. Being fulfilled/ability to overcome (a standalone enhancer of recovery)**

- Peace with others, **Felaphi**
- I am better than those that don't accept me, **Felaphi**
- Something good comes out of this illness, **Salaphi**
- I have a dream to generate income, **Selina**
- I am not as bad as others think I am, I have accomplished a lot, **Thobile**
- The war within me, **Thobile**
- Desire to overcome, **Welile**
- The joy of being included, **Winile**
- Determination to rise above constraints, **Winile**
- The joy of being valued by others, **Tholu**
- Motivated to win: hobby used productively, set goals, refused seclusion (to be put down by others) , **Tenele**
- Working hard, making goals, learning new things, **Eli**

## Appendix P: Summary of participants' stories

Name, Age, Distance, Educ., Yr living with schizophrenia	SUMMARY
<b>Nono</b> , 50, 26, Std. 2 (4), 2005	To hospital to refill medication in 2011, left by car, no money then admitted for a couple of days. Last admission 2009, Recov: can cut grass to make mats, can care for grandson, medication is good, good staff, had a 1:1 with nurse not working in the ward, <b>nurse talked like you</b> , when <b>grandchildren grandmother died</b> , nurse <b>encouraged forward</b> thinking, nurse said work on mats, have a break, implemented, it worked. Good relationship with husband (repeated x2), talks well with her, encourages balance between work and rest, enjoys working hard at home. Joined church, cleans at church, attend weekly prayer, share problems, prayer answered.
<b>Londi</b> , 30, 8, G. 1 (Recpt.), 2005	Doesn't believe in being better, sent to hospital by mother, told her in the morning that she was not well, and to go to hospital, enjoyed running away with boyfriend, abscond through the window, wanted cigarettes, no access at the hospital, not allowed, enjoyed hospital stay, enjoyed sex with boyfriend.
<b>Lulu</b> , 36, 4, None, 2001	Recov: not forgetting, being normal: stops talking to self, clean house, not write aimlessly, keep busy, child minder. Medication helped: repeatedx2. Want to work in the soup kitchen for orphans. Wants to resume attending church, had enjoyed youth programs. At the hospital played games, helped become better. Wants to go back to church become involved with cleaning activities, helps to be surrounded by church people makes her forget illness, get absorbed in helpful things, does not want to be alone at home. Wants to go to college to become a journalist.
<b>Eli</b> , 56, 20, F.3 (9), 1973	Recov: do many things, respect self, not stripping in public, can have a bath, not forget way home going to forest, stay at home in peace. Forgetful when unwell. Dr said studying hard, but books got lost when about to write JC. Taken by relatives to be prayed for, helped, but medication is very helpful. <b>Improvement</b> in hospital treatment, staff don't shout any more, directed by receptionist where to go. Stigmatised by seller of land, after father died, wanted land back, threaten to harm her physically, asked for prayers, disturbances stopped. Going to church helps, share problems others pray and encourage her, trust God to solve problem. Brothers and sisters supportive: give money for transport to hospital and to buy food, make me feel that I am not alone, thought I live alone. Taught at a preschool, place take for someone living near school, the worked as a cleaner at a hospital, it closed, now will train as a rural health motivator, also a member of red cross. Live alone mentioned x2(? Worried). <b>Improvement</b> at the hospital, people are becoming better. Only constraint is lazy patients, or excessive alcohol consumption
<b>Jojo</b> , 10, G. 1 (Recpt.), 1989	Recov: fewer problems, repeated many times. Became unwell, couldn't sleep, heard people talking. Medication is good, regular changing of medication now takes two tablets, feels good , ?involvement during change, nothing makes things better, endless problems, no wallis to get

Name, Age, Distance, Educ., Yr living with schizophrenia	SUMMARY
	grass to make mats for sale to generate income has good money, now sells peanuts (yearly) depending on harvest, rare organic chicken, customers buy on credit, don't fulfill promise: money not returned as agreed. Preoccupied with problems, eg where to find food, cannot think clear as a result. Husband retired due to health issues
Thobile, 50, 15, None, 1985	<p>Wants to be better so that she can help her children much better. Wants to go back to work. Worked as a gardener, ploughing vegetables, illness is restrictive: cannot do what she wants, illness consumes her strength. Wants to stop sleeping, sleeps after medication, medication makes her sleep. Solution: wants employer to accept her back to work, employer said she is not well yet, wants to start slow, gradually and gain strength gradually. Wants to work and not sit idly, waiting to be told by employer when she can return to work. Lack of employment: wants to sell vegetables to start being active. Medication very helpful, taking medication for a long time, relapsed when not taking medication, lost marriage through the illness, <b>also stressed by death of grandchild</b> + not taking medication. Stopped taking meds, cause she thought she was cured, will not stop taking meds, does not want to relapse. Nurse took <b>good care of her, washed her daily</b> repeatedx3, <b>gradually realized importance of having a bath, last bath herself with help of nurses, likes looking beautiful, given food repeatedx4</b>, and combed her hair, medication given at the right time. Having no stress makes her feel better x2, avoids talking a lot, <b>eating food makes her better</b>, no food at home: <i><b>"I even thought that my mother has been brought to life"</b></i> 7:134. Heard two voices, one bad and the other bad, telling he not to eat, sometimes over powered the bad, ate: then voice came back shouting at her that she ate poisoned food, had a 1:1 counseling with nurse, given skills on how to deal with voices, it worked, also given medication , then it stopped, now has normal dreams. Community: <b>cooks for orphans</b> soup kitchen, well accepted at the soup kitchen, arranging to return, had only stopped because of the illness, also involved in cleaning the royal kraal, and in community women activities, these helped to learn to talk and respect others. Medication has been important in her recovery. Feels happy to have brought <b>up 9 children as a single parent, children are now happily married.</b></p>

14, <b>Felaphi</b> , 64, 13, University degree, 1978	Went to Kenya to further her studies. Still not recovered, injured by pastor, not supported when daughter became pregnant premarital, instead he visited me at home, and blamed me for her pregnancy. Experienced a lot of stress from church, hence became unwell. Advised not to attend church, did not for a year, but this did not help. Illness started when she broke up with her boyfriend from Lesotho, he was controlling, refused her to attend a graduation ceremony where she was invited to participate, arguing that she was going to be seen by other men. Boyfriend later told her his family had arranged another lady for him to marry, a Mosotho, because she was Swazi. He was physically abusive, coerced her to get married at the district office, she refused, unfortunately she became pregnant with his child, he encouraged her to abort stating that nobody would marry her if with a child, she refused. However, contemplated aborting because she suspected rejection on
---	---

Name, Age, Distance, Educ., Yr living with schizophrenia	SUMMARY
	her return home, but did not want to live with guilt of having taken an innocent soul. Does not regret decision, accepted at home on her return; daughter is very support now: helped her finish building her house, gives her food and money. Illness triggered by work stress in 2001. Recovy.: reading and listening about forgiveness, tries to forgive, yet finds herself remembering part hurts. Lady at church hurts her, by making bad remarks. Learns from challenges faced, but still does not believe Christians should hurt each other, rather should be a place of peace and harmony. Comfort to realize that the <b>lady possible</b> had inferiority complex, she did not complete school, and her husband beat her. During admission, nurses were observant, saw that I was not sleeping, gave medication, helped, and managed to sleep. Nurses are caring, no long waits at the OPD, only waiting today because of police brought a patient. Live in <b>peace with people in the community</b> . Doesn't mind minor issues of people being jealous about her accomplishments. Content that her children are doing well, two are at the university, one is amongst the top 50 best students in the country. Teaches Sabbath school at church, very happy.

<b>Tholu</b> , 68, 3, Std. 5 (6), 1977	<p>Started being unwell when husband had extramarital affairs, caused a lot of distress. Took her livestock (cows), gave to second wife. Also took a lot of her belongings she had worked for with her children. Angry: wanted to beat them. Told by doctor to stop bothering her, did stop, and then died in 2000. <i>“Reward I get from someone called husband, need to tell myself that I was not born with this person”</i> Quickly changed the topic, said she wants to move on. Readmitted after the death of her daughter. Loss of appetite and weight when unwell, kept thinking about the problems. In hospital learnt how to bake from volunteers who came to teach us. Played netball at the hospital, made a lot of friends, then we could be allowed to go out on leave, shopping at Tiger City with my friends we were identified as getting better. One of the friends embarrassed her while they had gone out, undressed in public, and attributes this to not making the right choice. Children very happy when they visited, found her full of life, wearing shorts. Had fun at the hospital. <b>Accepted</b> her situation, but told self that she was in hospital, but wanted to become better, therefore decided to participate in all activities. Recovy.: use of available resources, sells avocado from tree at home, sells fruits, good management of money, with pension she gets, buys food, and gives to others. Good support from children voluntarily give her money, she does not need to ask. Have fun with her daughters and daughters in law. <b>Happy because children are doing well, believes she brought them up well</b>, one has built a big house in South Africa, another girl lives in Swaziland, got a loving husband, this makes me feel well in the brain. Believes God has helped her teach her children that it is not good to be involved in corruption, did not take anything from corruption; have been reprimanded in the past, if involved with corruption. <b>Involve with orphans support</b>, 34:722 in charge of making sure that they are well fed; ensure food is not stolen by those who prepare it.</p>
<b>Selina</b> , 34,12,	<p>Feeling better: doing things that would couldn't do when unwell. Use to hear voices of people discussing issues, debating <i>“I feel hot”</i> To be</p>

<b>Name, Age, Distance, Educ., Yr living with schizophrenia</b>	<b>SUMMARY</b>
---	----------------

F.1 (7), 2006	better: nurses did nothing, but gave medication to drink, not seen anything bad at the hospital, nurse give medication x2. At home mother encourages me to take meds at the right time; relationship with brother is not good: arguments over food, because I don't work, not bringing much home, wants to work and support her one year old baby. Opts to selling vegetables, needs money for stock. Child's father working, but not supportive, reported to social welfare, only gave little money (£10) once, therefore spends time thinking about where she can get money, get frustrated when thinking about where to get money. Also living with HIV, needs travel money to collect medication twice a month, this hinders recovery. Wants to focus on vegetable business, and not think about the father's child who does not give money. Given money by sister bought milk for the baby. Tablets help her to <i>"have a sound mind and to perform her duties."</i> Happy to live with family and not need to buy food, as she would in her own flat. Recommended outreach: to be given medication at the community, and not to be coming to the hospital on monthly bases.
<b>Tenele</b> , 22, 10, Std. 4 (5), 2008	Being better: not beating people for no reason, thinks this is because she was hearing voices of airplanes passing. Triggered by being given a hand shake by a stranger, fainted, became unconscious for a long time, relatives sent me to be prayed for, became conscious and normal. Mother gives me food at night when I am hungry, sister gives her money to come to hospital and going to church. Wants a better paying job, make sleeping mats for now, sell in Swaziland and in South Africa. Wants to restart school, in 2013, then study to become a police officer. Plans to study in South Africa, only mother is concerned that she might not take her medication. Was <b>beaten by staff at the hospital</b> , with a broom, <b>forced to go to seclusion</b> , refused. Observed to be tearful, agreed that I inform the matron (had a 1:1 session with her), refused to talk further because the experience was recent. Does chores at home, assists her mother. Problem: has a huge appetite
<b>Titi</b> , 55, 9, G.1 (Recpt.), 1975	My name is Titi, I am 60 years old, and I live about 8 miles away from this hospital. Nothing promotes my recovery from schizophrenia. I enjoy doing hand craft. I use to make bags from a special green white threaded plant. The problem was that I could not find buyers. I learnt this skill when I was still a student at high school. <i>Financial support</i> : Nothing at the moment. <i>(There was a moment of silence)</i> I have children, however, they do not give me money, and they only buy things for me. People in this hospital are good, even in the wards everything is alright. I don't like the seclusion. That room is very small. I have been fortunate, I have never been sent there. I am afraid that I would suffocate in that room, it is very small. Those who were severely disturbed benefited by being taken to seclusion because they could not abscond, but I wouldn't have been helped. I participate in community activities where we remove weeds from the chief's fields. I sometimes brew alcohol and sent to the royal kraal when the community is instructed to do so.
<b>Pholile</b> , 48,	Please refer to Pholile's story in appendix J

Name, Age, Distance, Educ., Yr living with schizophrenia	SUMMARY
10, F. 3 (9), 1995	
<b>Winile,</b> 48, 14, F. 2 (8), 1994	<p>Winile was 42 years during the interview; she lives 14 miles from the national psychiatric hospital. She studied up to form 2 (year 8), and was diagnosed with schizophrenia in 1994. There is no word, in the siSwati language, which refer to schizophrenia. Winile described her condition as the “illness of the brain.”</p> <p>Regarding recovery from this mental illness, Winile believes this is possible, mainly attributing this to the fact that she does not smoke and drink. She highlights that it is importance to take medication, and that because of information given by health professionals, she not likely to stop taking medication, stating that she must take it for the rest of her life. Winile attributes the cause of her three readmissions into the mental health hospital to her “breaking the law of the hospital.”</p> <p>Some of Winile’s indicators of recovery are: feeling well, good sense of hearing, absence of attacks from unseen people, not engaging in risky behaviours (entering under a moving car), beating others, being isolative, and doing house chores. Although Winile’s relative took her to be prayed for during an acute phase of the illness, she recalls that this did not help in any way. Nevertheless, she acknowledges that she has been given traditional medicine which she says makes her feel better. Regarding her experience of living with the mental illness, Winile indicated that she is not happy because her brain “gets lost” so that she becomes unable to be independent to do what she wants. She also states that others do not think well of her, she is misunderstood, and not accepted, for example after she informed her boyfriend about her mental illness he changed his behaviour towards her, leading their separation. On another note, Winile indicated that her relatives and significant others have accepted her as she is; for example, they cook, laugh and joke together, which she finds therapeutic, and she says it makes her feel happy and “comfortable.” According to Winile, she is not well accepted in the community. She stated that being involved in a community project working with children would make her feel fulfilled and rewarded, yet she is not only fully engaged with other fruitful projects, but the community refused to get her involved because she suffers with the “illness of the brain.” Despite some of the negative encounters Winile goes through in the community, she managed to find a group where she saves money and receives a lot of food at Christmas. She then shares with her children, who live away from her. Winile said that she is happy to contribute food to her sisters in law, with whom she lives with. Winile is not happy with the manner of treatment she received on her initial admission at the psychiatric hospital. Besides being beaten she had an experience where she was taken to seclusion for quarrelling with another patient. Winile said that in the seclusion there are no mattresses, so one has to sleep on the floor; food and medication are served last in seclusion. She repeatedly informed</p>

Name, Age, Distance, Educ., Yr living with schizophrenia	SUMMARY
	<p>me that she does not wish to be admitted into the hospital ever again, emphasising he bad experience. Winile’s wishes the hospital not to integrate the HIV services with those of mental health, because even thought she would like to speak with staff about the HIV and some of the challenges she encounters, she is unable to so, because there is no privacy when collecting the anti retroviral drugs (ARVs). Winile often wonders what people think of her when she first visit the mental health department, then goes to collect ARVs, within the OPD, she boldly confessed that she does not care any longer because she has told herself that “everybody has their own problems.”</p>



<p><b>Welile</b>, 38,22, F. 5 (11), 1998</p>	<p>Welile was 38 years during the interview, she completed her high school education (completed form 5 or year 11) and she lives 22 miles away from the SNPH. She was diagnosed with schizophrenia in 1998. She has been admitted to hospital several times, the last one being May 2014, and was discharged on the 31<sup>st</sup> August 2014. When she first became unwell Welile said that she felt dizzy, fell, saw things that were not seen by others, and a feeling that her brain was being disturbed. She also made unusual involuntary movements in her body. Welile said she hit her brothers, and would aimlessly run to public places, naked.</p> <p>Her mother took her to a private clinic where she was informed that she (Welile) did not have enough blood in her body, and as such little reached the brain, making her unwell. The doctor at the private clinic advised them to visit the SNPH where Welile said she was not treated well. In the wards she said if found fighting with another patient they were bitten by the odals (care assistants), and some of the nurses joined in. Then they were clocked up in seclusion, where there living conditions were unacceptable. Also, because she was not always unhappy, one of the odals was always verbally aggressive towards patients, whenever she came into the ward she could shout at them, and she called them ‘names.’ As a result she did not provide them with daily supplies, like toilet paper, making assumptions that they wanted food, when they asked from that kitchen. Welile reported this to the nurse, but feels nothing much was done because the lady continued to shout and called them ‘names.’ As such, she does not want to stay in the hospital again; she said she is much happy at home. Welile was taken to seclusion after she was found fitting with one of the patients, in an attempt to defend herself. There that she slept on a concrete floor, not even a mattress was supplied. Being winter, she was very cold. Following the fight with one of her peers, Welile’s stay in hospital was prolonged, and she was taken to ward where she was admitted when acutely ill. Even though she was unhappy about this, she did not report it to anyone. On another note, Welile said some members of staff were approachable, and they spent some time talking with patients. As such, she was able to tell one of them about the lady who shouted at them. At the hospital she was given food, felt supported in regaining lost skill, like bed making and taking a bath. Welile benefited from health talks that were provided by a student nurse who happened to be on placement during her admission. Concerning how others perceive her now that she lives with the illness of the brain, Welile said some think</p>
--	--

<p><b>Name, Age, Distance, Educ., Yr living with schizophrenia</b></p>	<p><b>SUMMARY</b></p>
--	-----------------------

	<p>that she is ‘mad’ all the time, and others discriminate her. However, her family, friends and neighbours understand her, and they also know when she is becoming unwell. She feels hurt when discriminated, she then prays and also benefits from going to church, she said the illness becomes better. After being discharged from SNPH once, her boyfriend asked her why she was admitted into hospital; Welile informed him that she suffered from an illness that caused her to fall. Her boyfriend kept quiet, and she feels that is an indication of not accepting her. Welile believes that she can recover from the illness of the brain, because, although she was taking her medication, she was not admitted for four years. She believes her relapses were a result of not taking her medication; she stopped because one of her tablets made her sleepy in class. Her prayer is to stop taking the medication, because of being stigmatised by others when does. Regarding what she likes doing, Welile said that she would like to open her preschool, and teach there, especially because she has a qualification in this area. Although she has not started teaching at preschool, she thinks that she would feel good in her mind, because she loves doing this.</p>
<p>35, <b>Salaphi</b>, 51, 13, Std. 5 (6), 1990</p>	<p>When unwell behaved like one possessed with animals, dancing with dancing gear, hearing voices: mother’s side, were clear, to hospital, beat them, illness after delivery, nurses listened, spent time with us advised on dealing with voices, talked in isolation, <b>just like now</b>, wrote experience goals and ambitions on a paper, felt good, <b>not instantly</b>, valued time spent with a professional. Must not be upset. Nurses were supportive, gave medication on time, patient with use when we were asleep, given food. Recov.: helped with house chores. Relapsed: forgot to drink medication on alternative days as recommended by Dr. Illness returned, prayed continuously. At home, brought me to hospital when I was well: was dressing up because I like it, said I was mad, accused her of stripping naked, swearing, and insulted swearing at those accusing me of being unwell. In hospital they wrote down what they said, did not listen to me, told me to keep quiet, gave me an injection, left and locked up in hospital, was aware of everything (laughed). Forced to take traditional medicine, smeared all over her, a traditional healer and hut at the homestead. Was restrained with a rope. Emphasised she knows herself, shouldn’t have be forced to take medicine and to come to hospital repeatedx4. Dancing at the in laws: cultural conflicts. Husband calls her a mad woman, even when having disagreements or arguments, answer him back: madness will get you one day, coping through laughter. Encourages her daughter who is living with the illness of the brain, tell her that others live with the illness too: even professionals, therefore illness should not stop her from getting what she wants or becoming what she wants to be, she can achieve anything. Encourage her to work hard. Work: a child minder, informed boss, initially refused to let her go to hospital, now changed. Nurses are good, took care of her. Beat another patient, told to stop. Taken to seclusion for not sleeping, reported by fellow patient, slept on the floor, no mattress, was thirsty no water drank from the toilet, couldn’t shout for help, drunk from the medication, nurses laughed at me for not eating because I told her that the food was poisoned (the beetroot).</p>
<p><b>Name, Age, Distance, Educ., Yr living with schizophrenia</b></p>	<p><b>SUMMARY</b></p>

	<p>Recov.: talk to people, don't stay alone eg sister in law, neighbours, enjoy being visited not me visiting them. Does a lot of work at home: collect fire wood, wash clothes, sell fruits and vegetables to others, clean and wash for people, get paid little. Missed being involved as a rural health motivator when unfairly admitted in hospital. Like caring for people, helped elderly when admitted at the mental, plate their hair, help bath them, did hand work sowing, crouching, feel good when working, feel pressed when not working, like finding something to do, like to be busy. In hospital, take to the laundry to fold washing, felt good, washed dishes after meals, respect nurse even though some were younger than me.</p>
--	--

1 **Appendix J Pholile's story**

2 **Voice 33** Pholile 48 years, 10mile away, Diagnosed in 1995, Form 3 (year 9)

3 Researcher: R Participant: P

4 R: May you please tell me your journey of the mental illness since it started.

5 P: It means...I can say that...since the illness started in 1995 they brought me to the psychiatry

6 hospital. I found that my small grandmother is educated and is used to hospital and is a

7 Christian. This really helped. They took me to Nazarene hospital, and there they transferred

8 me here. I found that it was very good; I realized that I became better immediately.

9 R: How did the illness start?

10 P: Oh! I was terrified. I was terrified. This was when I returned from church. I saw that there

11 were people coming towards me, these people were fighting. Ye...t, yet what really scared me

12 was that one of the prince wanted me, and I did not want to, was terrified through him. I then

13 could not sleep not sleep properly; when trying to sleep I could see him, I was pregnant at that

14 time, I could not sleep properly, I was terrified (*demonstrated terror on her face*) I even went

15 to church to request for prayers. The illness was a little better after the prayers, for about 10

16 months. After delivery I stayed for about a year, or maybe ten months. Then the illness started

17 again. Then my brain was confused, really, really confused, this was when I came from church,

18 I was just walking alone, I then felt like my mind was confused, usually in the morning, this

19 thing of getting terrified, this is how the prince did it, he made it in such a way that he made

20 me breath like the spirit was going to come out, I was so terrified, you see. I could see him at

21 times (*raised her voice*) this was when he was still alive he is dead now, and I was so terrified,

22 you see, this is when my mind would be confused, yet I was not very confused. I told the girls

23 I was sleeping with, because I went very early to work at nyandza, because we were praying

24 together with these girls at princes Pholile, at the bishop Nash, then I went to have a sleep over

25 with these girls, my child was with me at that time. I then went back to tell them, they then

**Commented [S1]:** Family support

**Commented [S2]:** Other's knowledge

**Commented [S3]:** Others' religious believe

**Commented [S4]:** Prompt hospital attendance (early diagnosis)

**Commented [S5]:** MI: being scared

**Commented [S6]:** Persecutory delusion

**Commented [S7]:** Life experience led to mental instability

**Commented [S8]:** Insomnia

**Commented [S9]:** Prayer: benefits

**Commented [S10]:** MI: being baffled

**Commented [S11]:** Other's influence to control one's body

**Commented [S12]:** ?ambivalent feelings

26 called the pastor to ask him to pray for me. He did pray for me, but the still brought me to the  
27 hospital. They then brought me here, I was not able to sleep. I could see, like I could see you  
28 standing here, I could see a lot of people's pictures, I could see people that were not there, and  
29 I could smell none existing strong smells, unusual smells. I felt like a lot of things were coming  
30 out, things like demons. Then they took me to hospital. The body had been walking for a long  
31 time, I could be walking for the whole night, I could not stop, I could also talk right through, I  
32 could talk, I walked none stop, my body was weak, it was very weak.

**Commented [S13]:** Hallucinations

**Commented [S14]:** Visual & Olfactory hallucination

**Commented [S15]:** Uncontrollable behaviour

33 R: What happened when you came to hospital?

34 P: Oh! When I arrived in hospital they admitted me, they gave me an injection, then I slept. I  
35 am not sure whether it was for 5 minutes, I don't know, what I know is that I managed to sleep.  
36 It felt like I was drugged, they just drugged me, the injection just drugged me. On my first  
37 admission I thinks I stayed here for about three months, or four, I don't remember very well,  
38 some where there, them I became better.

**Commented [S16]:** Injection

**Commented [S17]:** Being controlled by injection

39 R: What do you think promoted your recovery when you were at the hospital?

40 P: I could say....it helped me that.....that I got the injection, and that I listened to what the  
41 nurses were saying, because after you get the injection you want to eat, you were able to eat.  
42 And also it tells you what to eat, the food is available, there is no problem. The nurse had love  
43 with you, especially when you listen. You find that some are really sick, and some time they  
44 did not listen. That is not good.

**Commented [S18]:** Medication

**Commented [S19]:** Being obedient

**Commented [S20]:** Being able to eat

**Commented [S21]:** Nurses attitude: listening

45 R: Other talked about seclusion. Have you ever been in seclusion?

46 P: Oh seclusion! Seclusion is a place where you stay alone. When you get the injection, it seems  
47 like, yes the spirits go out, you see. I did feel a certain spirit going out of me. Yes seclusion is  
48 a good place, it is helpful to go to seclusion.

**Commented [S22]:** Isolation seclusion

**Commented [S23]:** One way seclusion therapeutic

49  
50 R: Did you like it in the seclusion?

51 P: Ah!!! Seclusion is not nice, nobody likes seclusion, sometimes you wanted to come out (*she*  
52 *laughed the researcher joined in and laughed*) You see, even though I think it helps, but you  
53 see, it makes you feel like you are in prison. You know, they post your food through the  
54 window, even you medication they post through the window, the nurse can see that...ayi...she  
55 is okay now to come out and be others. Otherwise you stay in seclusion.  
56 R: Have you ever been sent to seclusion?  
57 P: Yes I did, I had just arrived isn't it, I was admitted. I was not well. I was given an injection,  
58 I stayed in seclusion. You could stay there for three days, but if you don't want to take your  
59 medication you will stay there in seclusion until you listen.  
60 R: Oh! Does it mean that those who don't listen are sent to seclusion?  
61 P: No, no! Yes...yes even when you don't listen indeed, but also when you first come to the  
62 hospital, you are first sent to seclusion, because you are not well then. You stay there until you  
63 can listen and are able to drink the medication. The medication is good, it help you a lot, if you  
64 drink it well you become well.  
65 R: What else do you think promoted your recovery when you were in hospital?  
66 P: (brief silence) There is so much love, the nurse have love. The nurses have love.  
67 R: How did they show you this love?  
68 P: First of all they bring you parent in, they let her come to visit. They allow your mother to  
69 visit you, they take good care, they take you well. They take you like a person who is well. As  
70 you could do to a normal person, if you do anything wrong they will shout at you, just like you  
71 would to a normal person. They do need to shout at you sometimes, because the mind seem  
72 like it will get lost. You go back to become like a child, you just think like a child. There you  
73 go back to be normal. You lead, I was leading at the firm, I could hit the score, I was leader at  
74 the score.  
75 R: Which score, what do you mean?

**Commented [S24]:** Also seclusion feels like prison

**Commented [S25]:** Professionals decide on your wellness

**Commented [S26]:** Seclusion promotes compliance?????

**Commented [S27]:** ( not sure of indication for seclusion, professional explanation???)

**Commented [S28]:** Seclusion prescription for first admission, promotes recovery

**Commented [S29]:** Recovery will to adhere to others/professional & medication compliance

**Commented [S30]:** Affection from professionals (significant, repetition)

**Commented [S31]:** Professionals involvement in family visits

**Commented [S32]:** Caring professional

**Commented [S33]:** (Professionals' acceptance & understanding)

**Commented [S34]:** No stigmatisation, being valued

**Commented [S35]:** Equal, fair treatment

**Commented [S36]:** Reprimanded in a common acceptable way

**Commented [S37]:** Hospitalization promotes recovery

**Commented [S38]:** Work productivity

76 P: I mean at the firm where I use to work, we had to saw and we had competition amongst  
77 ourself, we compete in lines, the line that produced more clothes. You go back to being well,  
78 you really become well with this medication, you become well. You get home and sleep, you  
79 feel pressured, you sleep, you sleep, and then you become better like the others, you become  
80 better like the others.

**Commented [S39]:** Productivity while having fun.

**Commented [S40]:** Rest after discharge

**Commented [S41]:** (Ability to perceive, rest, adjust to community living through difficult times, medication side effects).

81 R: You mentioned that you felt better because nurses allowed your mother to visit you in  
82 hospital. How did you feel you about when she visited?

83 P: It made me feel much better, because when the others have visitors and you don't, you end  
84 up becoming ill, you become ill, even though you are in hospital, you become unwell. They try  
85 giving you medication, but you become unwell, you still become unwell. You hear needs its  
86 own things.....yes the body also needs what belongs to it, I can just say God's spirit needs it

**Commented [S42]:** Universality, get visits like others

**Commented [S43]:** Significant others hospital visits promote recovery

87 own thing. The body needs its own thing, it need love, and when your relatives visits, it really  
88 feels good. Even the food, the nurses gave us food, there is a lot of food. Because when you go  
89 home you get hungry you will be eating sour porridge, you get tire of eating such sour porridge  
90 all the time. When my grandmother gives it to me, I tell her that I want to go back to hospital;

**Commented [S44]:** Family visit meet emotional need, recovery more than physical needs (medication)

**Commented [S45]:** Adequate nutrition

**Commented [S46]:** Food variety

91 she asks me, do you really want to go to hospital. I tell her yes, I am tired of eating this sour  
92 porridge. Grand mother would take me to hospital, she sent me to the mental hospital. The  
93 doctor would ask my grandmother, how is Hlengiwe, does she eat well, hayi! I could tell the  
94 doctor no, no, I want to stay here! (*she laughed, the researcher joined in*). You see we eat well  
95 here, the food makes us well. You really become better. They re-admitted me some time back.

**Commented [S47]:** Hospital - Enough food

96 They made a false accusation that I was becoming unwell.

97

98 R: Who made the false accusation?

99

100 P: It is my mother's uncle. I attended a church service, he is not a Christian himself you see.  
 101 He is a polygamous man, he then told people that I did not sleep. In the morning I drank my  
 102 medication, but I confused the medication, then I became very sleepy, I was sleepy. I had put  
 103 my laundry, then I woke up, I told myself that I needed to buy sunlight, ah! I then saw a car.  
 104 The people in the car said we want Pholile, I only came to look for sunlight and Vaseline, I had  
 105 to travel to Mbabane. I thought I should buy a few things for my child, and I would go to  
 106 Mbabane a bit later, I wanted to rest for a bit. I want to stay and attend some services, then go  
 107 to Mbabane. Awu! They said I am not well I was said to be mad, they told lies about me, stating  
 108 that I was not sleeping well. They took me to the doctor and told him all this. The doctor did  
 109 not speak much, all he knows is that this is a patient, she is mad. This is why I am now so fat,  
 110 yet I was getting ready to go to Nazarene bible college at Siteki where I was going to study as  
 111 a pastors. This happened three years ago, yes this is the third year. Then they gave me an  
 112 injection, I was not ill at all. Now this injection makes you feel sleepy, you feel sleepy until it  
 113 wears off from your body.

114 R: Please tell me more about the false accusation, that you were not well, while you knew  
 115 that you were well.

116 P: I was very well. I was only excited that I was going to Manzini to refill my medication,  
 117 that's all. Yet that is a polygamy family. Even though my father had many wives, I did not live  
 118 amongst a polygamous family, my grandmother brought me up, I only visited my father on a  
 119 few occasions. But in this area one of the people did not like me, she tortured me and made me  
 120 to quarrel in this family. I had my house within the home stead, not far from the others. This  
 121 lady would leave her house to come to mine, and caused trouble; she caused trouble and  
 122 mocked me. That.....at home I lived with my mother before she died, and my two children. We  
 123 did not have any problem. It was not until one of my half brothers started causing trouble. He  
 124 smokes weed, he is rude. This weed cause him to be confused, things were not going well, we

**Commented [S48]:** Stigma – being misunderstood by others

**Commented [S49]:** Being in control

**Commented [S50]:** Professional's assumption, not being listen to by doctor

**Commented [S51]:** Medication side effects (negative effect on self-esteem)

**Commented [S52]:** Mistreatment, medication side effects (restricted independence)

**Commented [S53]:** Stigma: being misunderstood by others

**Commented [S54]:** Family/others conflicts, quarrels

**Commented [S55]:** Conflict with others



125 ended up leaving the homestead. He chased us out of the homestead, stating that we should go  
126 out because that was his mother's property. We went and lived with my uncle at Lobamba.  
127 When we got there it was war again. Oh no, we found another war. You know there was this  
128 lady at the homestead; she just wanted to fight all the time. You know one day I was sorting  
129 my children's clothes; I burnt the ones that were ripped. She started telling everyone, she is  
130 mad, she is mad. Even my child, a little boy, I would think that my child had gone to school,  
131 but no she would force my child to stay at home and do chores for her. I realized that she did  
132 not go to school, and I asked her why she missed school, she told me she was being sent by  
133 this lady. This lady would come to my house and insult me, she would insult me and insult  
134 me...she would shout on the other side, saying "this mad lady, this mad lady." I was then called  
135 a mad person. She does have a brother who is also mad; by he was working at the research  
136 centre. I really did not understand this lady; she would provoke me, and provoke me for no  
137 reason. I could ask myself "what have I done to this lady to be provoked like this?" she never  
138 stopped; she provoked me and provoked me. One day I answered back, I was going to fetch  
139 water, she did the same thing, calling me a mad person, this made me so upset, I was also  
140 disturbed in my mind, and I had no peace in my spirit. I then left this place; I went to live at  
141 Lobamba.

142 R: Tell me more about what happened when you told the doctor that you were not ill.  
143 P: I did tell the doctor (*spoke with a soft voice, with emphases*) told the doctor that I was not  
144 ill. But they continued to hold me and injected me. I told them that I was okay. I was just going  
145 to buy a washing soap to do my laundry, this lady told the people that I was not well, and they  
146 took me in a car and brought me to hospital. When I came to the hospital, I felt I should phoned  
147 my pastor and reported that they took me to hospital even though I was not ill. I felt that what  
148 they were doing to me was not right. I phoned the pastor. The pastor came to see me in hospital.

**Commented [S56]:** Conflict with others

**Commented [S57]:** stigmatisation

**Commented [S58]:**

**Commented [S59]:** stigma

**Commented [S60]:** Persistent stigma and torture from others, emotional torment

**Commented [S61]:** Treatment without consent, one has capacity

**Commented [S62]:** Not being listen too

149 They continued to inject me, even though I told them that I was not ill, they still gave me the  
 150 injection. Now this injection has made me to gain weight, yet my weight was okay.  
 151 R: When did they force you to be admitted in hospital?  
 152 P: This was in 2012, my second admission to hospital. I us to suffer from headaches because  
 153 this lady would talk a lot, and she would insult me a lot. She would provoke me early in the  
 154 morning, or she could accuse me of doing something I never did. Then I could feel my head  
 155 aching, it feels like it would split, it was hurting. I started having pains everywhere; I could feel  
 156 that I was getting hurt through this girl.  
 157 R: Am I understanding you well that you become unwell if or when you have conflicts with  
 158 others?  
 159 P: Ahaaaa..... hu.....m.....yes, you are not supposed to be provoked by anyone. You must not  
 160 be tortured or shaken; you must be at peace at all times. For example, I don't work, I don't  
 161 wake up to go to the boss, I still have my various needs. I have a step mother, she has my  
 162 money, she does not want to give it to me, I....I...when I have had an injection, I must listen  
 163 to the injection, I feel like sleeping, you find that you sleep a bit, you sleep a bit, you sleep and  
 164 sleep a little, instead of resting properly, the step mother does not support you, she tortures you,  
 165 and does not understand you. Unlike you parents, she also torturers your children, she tortures  
 166 them. You find that she will take you child, she will take your child and pretend that she loves  
 167 you child, not that she loves the child, she wants to use your child in her home, her girls sit on  
 168 beds, you see, her children sleep on the bed, they just roll on the bed, and your child will be  
 169 working and serving them. They get angry at my children and torturer them. I then stopped my  
 170 children from going to the step mother. I told the step mother to stop, and I asked her not to  
 171 touch the child. My life is so difficult now, I have no money, yet my money is being withheld  
 172 by the step mother. There is not getting up to go to a boss to be, I don't have that strength  
 173 within me, it is difficult for me.

**Commented [S63]:** Forced treatment, professionals not listening

**Commented [S64]:** Medication side effects, low self esteem

**Commented [S65]:** Physical symptoms of stress

**Commented [S66]:** Emotional instability

**Commented [S67]:** Financial constraint

**Commented [S68]:** Financial exploitation

**Commented [S69]:** Medication side effects, need for support from significant others

**Commented [S70]:** Abuse of one's children

**Commented [S71]:** Unfair treatment of those significant to you

**Commented [S72]:** Confrontation of problem source

**Commented [S73]:** unemployment

**Commented [S74]:** Lack of inner strength (motivation, will power??)

174 R: What have you done about the money that is being held by your step mother?

175 P: There, regarding that, I have asked God's servant, and the church to pray for me. I have been  
176 asking from others to help me, asking for offering. They encourage me that I will be better, and  
177 they support me with money. When I first came to this place, Lobamba, my body was painful  
178 everywhere. I then slept. Concerning money for I go out to town to ask for support. (*moment*  
179 *of silence*).

180 R: How do you find staying at Lobamba?

181 P: E.....mm, I have been living there for..... this is my second year. We.....ll, we...ll,  
182 living there is okay, but I have a problem with the tenants. The tenants are rude. You find that  
183 they don't talk well with children, they torturer and intimidate children, they are rude, they  
184 are so rude. The tenants are a problem. The princes and princes are okay, they just sit, and  
185 they cause no problems.

186 R: Do you live with your children?

187 P: No I don't live with them. They live with their father. They usually visit me during school  
188 holiday. It makes me feel good to see them, I am happy when they visit me.

189 R: What make you feel better at Lobamba where you live?

190 P: It's just I have a rest, I don't rest much, but the little rest I have makes me feel better. I just  
191 sit and rest at the moment, I am useless, but I ask for support so that I can pay rent. I spoke  
192 with the prince (who is also the landlord), he was connected with my mother. He is aware of  
193 my situation, that my step mother, a Mozambiquen by origin, sold our property at Zakhele, she  
194 took the money, we have nowhere to live now, we are stranded. Imagine you have children,  
195 you just live.....you now live by God's grace. You just hung up to the cross, I am looking  
196 unto the King to fight for me. My father separated with this step mother, he told her to go away,  
197 my father chased her. When the house was sold she was the first one to buy it, when the money  
198 was supposed to come out she with held it, we are now struggling.

**Commented [S75]:** Support from church

**Commented [S76]:** Confidence in the support of others

**Commented [S77]:** Receives financial support from others

**Commented [S78]:** Support from community, town

**Commented [S79]:** Trouble from others, affect children

**Commented [S80]:** Visit from children

**Commented [S81]:** Family visit

**Commented [S82]:** Having time out

**Commented [S83]:** Less energy from within (?low self esteem)

**Commented [S84]:** (over dependency on others

**Commented [S85]:** Hope in

199

200 R: Is there anything that was done in court about this?

201 P: I did go to the court...at the magistrate....e..hh!! at the master's court. They told me that

202 there was no file. I said let me go to the Provident Fund to check, I found that there was no

203 money. But God helped me there, because that is where they told me where all the accounts

204 books were which my father had. They told me that this booklet is with this one, this is with

205 this one, and this was with that other one. My father had three of us from different mothers, I

206 am the only from my mother. My other two half siblings are giving me a problem, they don't

207 make my life pleasant, I am struggling now because of them. The other step mother are a big

208 problem. Even when you are sited in town, you find that their children start gossiping about us,

209 they laugh at us, you can actually see that she is gossiping about you to her friend. She gossips

210 and gossips and gossips, even the insults, they insult you. They are bad, really bad. Even when

211 she passes next to you. You feel a lot of pain, she has spirits that this girl spread to you, she

212 spreads some of them to you. The other one, you find that you are sat next to her, you will feel

213 a sharp pain pricking you on the chest (*she pointed to her chest where the pain is felt*). My child

214 also, once I was her, and she told me mum I am dying on the chest. Then, God had showed me

215 that this lady is evil, she put something her (pointed to her chest).

216 R: How are you coping with this situation?

217 P: Hayi!!! It is bad, the situation is bad. It is so bad, just like now, I have been called to

218 marriage, it is so very bad now.

219 R: Please explain what you mean when you say you are called to marriage.

220 P: I me.....an. I me.....an God has given me the gift of marriage and preaching. This means

221 that I have to get married, and preach. I need money for my wedding; the money is not coming

222 out! There is so much conflict now, they don't agree, they are now insulting me, they insult

223 me, they torture my children. We are always fighting with my half siblings. You preparing for

Commented [S86]: Perpetual distress

Commented [S87]: Stigmatisation

Commented [S88]: Non invisible torture

Commented [S89]: God's help

Commented [S90]: Financial constraint, restricts social progress

224 a wedding, people fight. It is difficult. Because this demon was moving around, causing  
225 confusion everywhere. What was happening there would happen there, it would happen there,  
226 here and there, and there, just like that. It is so locked now, it is only grace.

**Commented [S91]:** Family conflict hinder progress

227 R: What does your partner say about this?

228 P: That you are given by God. God will give me. He is not here yet, but God will give me when  
229 the time comes. God is still preparing me, so that I will be ready when the time comes. God is  
230 still sorting this money issue where Satan had blocked me, because there is nothing impossible  
231 with Him. You just need to focus on him. He will open away, he is faithful to do this, you have  
232 to be quiet and wait, and do whatever her wants you to do.

**Commented [S92]:** Hope that things will get better through supernatural intervention

233 R: From what I gather, you seem to benefit from your religious values.

234 P: Oh yes! I get a lot of help through God. You know, just like me, I get a lot of help at church.  
235 You me, just like me, I don't wake up at the moment, but I get a lot of support from the church,  
236 like the church I go to, at pastor Justice. You don't have uniforms you have a child, just like  
237 me, you can get your child's uniform, you get that sort of help. You just abide with the King;  
238 God helps you and meet you at your point of need. You find people helping you; you only have  
239 to hold on to him.

**Commented [S93]:** Community help, church support

240 R: Thanks a lot for sharing with me such sensitive issues. You appear to be positive women,  
241 with determination to succeed, which is good.

242 P: Yes if you trust God, he open for you big opportunities, it is amasing to rely on him. This  
243 is what keeps me going.

**Commented [S94]:** Continuous belief and trust in God makes others want to help

244 R: What are some of the things that you think could be done either at home or in the hospital  
245 that could promote your recovery from the illness of the brain?

246 P: Eh!.....Eh.....I am looking at this thing that happened to me, it really hurt me (her voice  
247 became loud). That I was given an injection when I was well, I was not ill. This injection hurts  
248 your life, you find yourself being dragged on the floor. That I was given an injection when I

**Commented [S95]:** Trust in God gives hope for better things coming

**Commented [S96]:** Emphases on bad experience

**Commented [S97]:** Mistreatment, wrong diagnosis

**Commented [S98]:** S.E. lead to regression

249 was not ill, this has really hurt me. All along I had no problem, but now I was given this  
250 injection, this hurt me.

251 R: Do you still get the injection?

252 P: No, it was only for that time.

253 R: Thank you for mentioning this. It was my concern as well. From what I gather you feel  
254 like nobody listen to you.

255 P: Oh yes, this really hurt me, it hurt me a lot.

256 R: What have you done about this or what would you like to do about it?

257 P: Well I didn't do anything. I did tell the nurse who was giving me an injection that I was not  
258 ill. But because I was talking to much trying to defend myself, I think she said, she is shouting,

259 she is ill indeed, she needs the injection. Yet I did not need the injection. The only problem I  
260 had was at home, yet because I believe in God, I do pray, he helps you when you are in need.

261 Just like where I live now, there problems are there, there is a lot of noise at times, but God  
262 helps me and removes the things that cause trouble. But the injection just kills you. You know

263 I use to come to the hospital and tell them that I am not okay, I am not okay, I am hungry, and  
264 they gave me food and I went back home. This injection made me to swell, I became fat. I

265 don't take that injection any more, I just take the tablets, what is it, Oh! I take olanzapine and  
266 artane. These are good, I am happy with my medication. The only thing is that I do feel tire,  
267 and I think I will sleep when I get home, I feel sleepy.

268 R: What would you like to be done about this issue of being given an injection when you we  
269 not ill?

270 P: I want the staff at the hospital to listen to patients, not to just inject them without listening.  
271 You know I met a pastor when I was admitted here, he was in seclusion. I was shocked that he  
272 was here, he said to me hey! I was stood at the bus rank, holding my bible, the police came to  
273 me, they said, we are told by this person that you are not okay, you are mad, you are not well,

**Commented [S99]:** ?professional wrong diagnoses introduction on problem

**Commented [S100]:** Professionals: Miss diagnoses, not being listened to

**Commented [S101]:** Professionals: assumption

**Commented [S102]:** Religious believe

**Commented [S103]:** Distress from mistreatment

**Commented [S104]:** Physiological needs met at the hospital

**Commented [S105]:** SE from medication

**Commented [S106]:** Professionals must listen to clients

274 get in here. He said this is how I am here. The pastor said he does not wish this to happen to  
275 anyone else, and even to happen to him again. This is my wish as well, that this will never  
276 happen again. That I will be given an injection when I am not sick, I felt that I was not sick,  
277 because I know myself. I know my illness. I know the importance of taking my medication,  
278 and I don't want to die because I have my children. So I don't know why they forced me to get  
279 that injection. I take my medication properly. This injection wasted my time because it made  
280 me feel like I was being dragged on the floor. I felt like I was locked in, yet life was moving,  
281 this was a waste of time.

282 R: Even though I will not mention your name, I will inform the management of the hospital  
283 about the experience you went through, and will inform them that you want staff to listen to  
284 patients and discuss the best alternative treatment, rather than to impose treatment to them.  
285 Thanks a lot for your time. Do you have any questions or anything else you would like to tell  
286 me?

287 P: No I don't have any questions. In the past though they said we should bring our PIN number  
288 so that they could give us money every month. We did this but it did not succeed, we did not  
289 get the money (*she laughed*). They told us money was coming, we were very happy, but no  
290 money came. They promised to give us money, we never got any.

291 R: I am not sure about that. Maybe the nurses at the OPD might know if you ask.

292 P: Ah!! I would ask another time when I return for my month refill.

293 R: Thanks very much for your time.

294

295

296

297

298

**Commented [S107]:** Others not to go through the same bad experience

**Commented [S108]:** Desire to comply with treatment, something worth living for

**Commented [S109]:** Mistreatment retards progress, low esteem

**Commented [S110]:** Financial support did not go through

299 **Reflection:**

300

301 • This participant encouraged me because she was open and chatty about her story.

302 • She presented as a strong believer in God, and seemed to receive comfort and

303 encouragement from her belief and the church

304 • At one point I felt angry about the step mother who took the money from the sale of

305 the property, and the fact that the documents were missing at the magistrate court. I

306 felt sorry for this lady

307 • I wondered what happened to the initiation of ? benefits for patient living with mental

308 illness. I would like to explore this further, at a later date.

309



Appendix K  Emergent Themes (chronological with line & page no.s)	Original Script to Exploratory comments (right) Descriptive, Linguistic, Conceptual comments  Voice 33 Pholile; Form 3 (9); Diagnosed: 1995; 10 miles away
<p>Family support: knowledgeable and a Christian (1:5,6)</p> <p>Illness: horrible, terrible, tortured, horrifying experience (1:10-12)</p> <p>First encounter: came from church (1:10)</p> <p>Seeing being attacked (1:11)</p> <p>Insomnia (1:15)</p> <p>Solicit help at church, benefited 10/12</p>	<p>Researcher: R    Participant: P</p> <p>R: May you please tell me your journey of the mental illness since it started.</p> <p>P: It means...I can say that...since the illness started in 1995 they brought me to the psychiatry hospital. I found that my small grandmother is educated and is used to hospital and is a Christian. This really helped. They took me to Nazarene hospital, and there they transferred me here. I found that it was very good; I realized that I became better immediately.</p> <p>R: How did the illness start?</p> <p>P: Oh! I was terrified. I was terrified. This was when I returned from church. I saw that there were people coming towards me, these people were fighting. Ye...t, yet what really scared me was that one of the princes wanted me, and I did not want to....., I was terrified through him. I then could not sleep not sleep properly; when trying to sleep I could see him, I was pregnant at that time, I could not sleep properly, I was terrified (<i>demonstrated terror on her face</i>) I even went to church to request for prayers. The illness was a little better after the prayers, for about 10 months. After delivery I stayed for about a year, or maybe ten months. Then the illness started again. Then my brain was confused, really, really confused, this was when I came from church, I was just walking alone, I then felt like my mind was confused, usually in the morning, this thing of getting terrified, this is how the prince did it, he made it in such a way that he made me breath like the spirit was going to come out, I was so terrified, you see. I could see him at times (<i>raised her voice</i>) this was when he was still alive he is dead now, and I was so terrified, you see, this is when my mind would be confused, yet I</p>

**Comment [S1]:** Family support, one who is knowledgeable, and a Christian

**Comment [S2]:** Other's knowledge

**Comment [S3]:** Others' religious believe

**Comment [S4]:** Support from educated religious significant others and prompt hospital attendance (early diagnosis), leading to quick recovery. In her story first significant comment in relation to her experience is the role played by her small grandmother in enhancing recovery.

**Comment [S5]:** Experience of illness: horrible, terrible, scared, tortured, horrifying. Use of exclamation word to further indicate horrible experience

**Comment [S6]:** I wonder why it was on her return from church

**Comment [S7]:** Being attacked ?Persecutory delusion

**Comment [S8]:** In real life ? the prince wanted her for a wife, or was she raped and reliving her experience? In order to understand this, there is no

**Comment [S9]:** Life experience led to mental instability. Having nightmare as a result of past

**Comment [S10]:** Insomnia. Did this actually happened or it was a dream, or maybe a delusion,

**Comment [S11]:** Whose child was this?

**Comment [S12]:** Insomnia, repeated, emphasized. Relived the experience.

**Comment [S13]:** Seeking help at church illness became better

**Comment [S14]:** Prayer: benefits, ten months symptom free

**Comment [S15]:** Extreme confusion, after church, walking alone. Same trigger as during the

**Comment [S16]:** MI: trigger-unknown

**Comment [S17]:** Other's influence to control one's body

**Comment [S18]:** The terrible experience heard in her voice, suddenly spoke loudly

<p>Second episode: brain confused, came from church, alone (1:19)</p> <p>Trigger: illness made by prince, causing her to breath as if to take out the spirit(1:21)</p> <p>Not confused, ?relieved past experience (1:25)</p> <p>Support through prayer with friends (1:26)</p> <p>Then sent to hospital(2:30)</p> <p><b>Hallucinations:</b></p> <p>Visual: people's pictures (2:32)</p> <p>Olfactory: none existing smells (2:33)</p> <p>Tactile: things like</p>	<p>was not <b>very confused</b>. I told the girls I was sleeping with, because I went very early to work at nyandza, because we were praying together with these girls at princes Polile, at the bishop Nash, then I went to have a sleep over with these girls, my child was with me at that time. I then went back to tell them, they then called the pastor to ask him to pray for me. He did pray for me, but they still brought me to the hospital. They then brought me here; I was not able to sleep. I could see, like I could see you standing here, I could see a lot of people's pictures. I could see people that were not there, and I could smell none existing strong smells, unusual smells. I felt like a lot of things were coming out, things like demons. Then they took me to hospital. The body had been walking for a long time, I could be walking for the whole night, I could not stop, I could also talk right through, I could talk, I walked none stop, my body was weak, it was very weak.</p> <p>R: What happened when you came to hospital?</p> <p>P: Oh! When I arrived in hospital they admitted me, they gave me an injection, then I slept. I am not sure whether it was for 5 minutes, I don't know, what I know is that I managed to sleep. It felt like I was <b>drugged</b>, they just <b>drugged</b> me, the injection just <b>drugged</b> me. On my first admission I think I stayed here for about three months, or four, I don't remember very well, some where there, then I became better.</p> <p>R: What do you think promoted your recovery when you were at the hospital?</p> <p>P: I could say....it helped me that.....that I got the injection, and that I listened to what the nurses were saying, because after you get the injection you want to eat, you were able to eat. And also it tells you what to eat, the food is available, there is no problem. The nurse had love with you, especially when you listen. You find that some are really sick, and some time they did not listen. That is not good.</p> <p>R: Other talked about seclusion. Have you ever been in seclusion?</p> <p>P: Oh seclusion! Seclusion is a place where you stay alone. When you get the injection, it seems like, yes the spirits go</p>	<p><b>Comment [S19]:</b> Not really confused, but this was a re-lived bad experience. This could be evidence of Polile reliving her experience as opposed to seeing this not visible to others.</p> <p><b>Comment [S20]:</b> Finds help from prayer partners, friends. A sense of closeness and support</p> <p><b>Comment [S21]:</b> Prayed for first, then sent to hospital. Probably because prayer helped her get better for 10/12 before the next episode</p> <p><b>Comment [S22]:</b> Insomnia</p> <p><b>Comment [S23]:</b> Hallucinations. First time mentioned seeing people that were not there, strong unusual smells.</p> <p><b>Comment [S24]:</b> Visual &amp; Olfactory hallucination</p> <p><b>Comment [S25]:</b> A lot of things coming out of her body. Possible tactile hallucinations.</p> <p><b>Comment [S26]:</b> Uncontrollable behaviour, continuous walking, talking. This led to physical exhaustion. Evident tiredness on using emphasis in word: 'weak, very weak'</p> <p><b>Comment [S27]:</b> Given an injection, helped, desired to sleep, slept</p> <p><b>Comment [S28]:</b> Being controlled by injection making progress or action slow, and difficult</p> <p><b>Comment [S29]:</b> The injection dragged me: unable to control being pulled, not necessarily resting, but being controlled while one is powerless. repeated this word 3X in one sentence. So the sleep</p> <p><b>Comment [S30]:</b> Medication helped to become better. What about the experience of being dragged</p> <p><b>Comment [S31]:</b> Being obedient</p> <p><b>Comment [S32]:</b> Being able to eat. Attended physical needs.</p> <p><b>Comment [S33]:</b> Nurses attitude: listening. Nurses' love was on condition you listed</p> <p><b>Comment [S34]:</b> When unwell it could be difficult to listen, pausing problem to nurse' care?</p> <p><b>Comment [S35]:</b> Alone, lonely, isolation seclusion</p>
---	---	---

demons coming out (2:34)	out, you see. I did feel a certain spirit going out of me. Yes seclusion is a good place, it is helpful to go to seclusion.
Uncontrollable behaviour: walking, insomnia, became weak (2:35)	R: Did you like it in the seclusion?
Injection: helped to sleep (2:41)	P: Ah!!! Seclusion is not nice, nobody likes seclusion, sometimes you wanted to come out <i>(she laughed the researcher joined in and laughed)</i> You see, even though I think it helps, but you see, it makes you feel like you are in prison. You know, <b>they post</b> your food through the window, even your medication <b>they post</b> through the window, the nurse can see that...ayi...she is okay now to come out and be others. Otherwise you stay in seclusion.
Rough experience of the medication: 'dragging' me (2:43, 44)	R: Have you ever been sent to seclusion?
Benefits of the injection (2:48)	P: Yes I did, I had just arrived isn't it, I was admitted. I was not well. I was given an injection, I stayed in seclusion. You could stay there for three days, but if you don't want to take your medication you will stay there in seclusion until you listen.
Listening to nurses (2:49)	R: Oh! Does it mean that those who don't listen are sent to seclusion?
Nurses' conditional love: listen/obedient (2:51)	P: No, no! Yes....yes even when you don't listen indeed, but also when you first come to the hospital, you are first sent to seclusion, because you are not well then. You stay there until you can listen and are able to drink the medication. The medication is good, it help you a lot, if you drink it well you become well.
Seclusion: Lonely, (2:56)	R: What else do you think promoted your recovery when you were in hospital?
Little help: spirit left me (2:57); to get better ( 3:68)	P: (brief silence) There is so much love, the nurse have love. The nurses have love.
Compulsory on admission(3:67, 72)	R: How did they show you this love?
	P: First of all they bring your parent in, they let her come to visit. They allow your mother to visit you, they take good care, they take you well. They take you like a person who is well. As you could do to a normal person, if you do anything

**Comment [S36]:** One way seclusion therapist where spirits go away

**Comment [S37]:** Seclusion a good place? Even though felt alone, its still a good place: spirit goes out.

**Comment [S38]:** She appeared to have suppressed feelings about seclusion, did not want comment on this issue, hence depicting it as a good place. She later wanted to say it as it is: 'nobody likes seclusion,' wanted to leave seclusion. Seclusion is like a prison, where you are locked up, restricted area. Sense of possible restrictions and limitations. Exclamation language used to indicate intensity of feelings, not a good place.

**Comment [S39]:** Food and medication given through a window. Use of a figurative speech to convey feelings of being treated differently, in an abnormal fashion. Although she does not elaborate on the posting of the food and medication, regard

**Comment [S40]:** Professionals decide on your wellness

**Comment [S41]:** Seclusion promotes listening what sort of listening? Possibly compliance????

**Comment [S42]:** ( not sure of indication for seclusion, professional explanation???)

**Comment [S43]:** Seclusion prescription for first admission, promotes recovery?

**Comment [S44]:** Recovery: will to adhere to others/professional & medication compliance

**Comment [S45]:** Being better is influenced by how one drinks his medication.

**Comment [S46]:** Affection from professional (significant, repetition)

**Comment [S47]:** Evidence of nurses' love: allows parents' visits (could they normally stop th

**Comment [S48]:** Caring professional

**Comment [S49]:** Professionals' acceptance & understanding. Being treated like a normal person

**Comment [S50]:** No stigmatisation, being val

**Comment [S51]:** Equal, fair treatment

Not nice, disliked (3:60)	wrong they will <b>shout</b> at you, just like you would to a normal person. They do need to <b>shout</b> at you sometimes, because the mind seem like it will gets lost. You go back to become like a child, you just think like a child. There you go back to be normal. You lead, I was leading at the firm, I could hit the score, I was leader at the score.
A prison, encaged (3:62)	R: Which score, what do you mean?
Compulsory on admission(3:72)	P: I mean at the firm where I use to work, we had to saw and we had competition amongst ourselves, we compete in lines, the line that produced more clothes. You go back to being well, you really become well with this medication, you become well. You get home and sleep, you feel pressured, you sleep, you sleep, and then you become better like the others, you become better like the others.
Discharge from seclusion based on client's will to comply (listen) (3:71,72,74)	R: You mentioned that you felt better because nurses allowed your mother to visit you in hospital. How did you feel you about when she visited?
Medication beneficial, if well taken	P: It made me feel much better, because when the others have visitors and you don't, you end up becoming ill, you become ill, even though you are in hospital, you become unwell. They try giving you medication, but you become unwell, you still become unwell. You heart needs its own things.....yes the body also needs what belongs to it, I can just say God's spirit needs it own thing. The body needs its own thing, it needs love, and when your relatives visit, it really feels good. Even the food, the nurses gave us food, there is a lot of food. Because when you go home you get hungry you will be eating sour porridge, you get tired of eating such sour porridge all the time. When my grandmother gives it to me, I tell her that I want to go back to hospital; she asks me, do you really want to go to hospital. I tell her yes, I am tired of eating this sour porridge. Grand mother would take me to hospital, she sent me to the mental hospital. The doctor would ask my grandmother, how is Polile, does she eat well, hayi! I could tell the doctor no, no, I want to stay here! (she laughed, the researcher joined in). You see we eat well here, the food makes us well. You really become better. They re-admitted me some time back. They made a false accusation that I was becoming unwell.
Nurse's love: re-enforces: allow family bond(3:80,81)	
Nurse: acceptance, not stigmatise me (3:82)	

**Comment [S52]:** Reprimanded in a common acceptable way. There is an acceptable, well tolerated level of shouting, to enforce boundaries encourages mature behaviour. Because when unw one thinks like a child. She associates reasoning a that of a child so that nurse' shouting is a form of guide and an attempt to encourage adult reasoning an indication of being well.

**Comment [S53]:** Hospitalization promotes return to normal, and once discharged, one becomes an expect at her work, being more productive.

**Comment [S54]:** Work productivity

**Comment [S55]:** Productivity while having fun. After hospitalisation one returns to her normal state of function.

**Comment [S56]:** Rest after discharge life after hospital discharge. Feel pressured; possibility pressured to keep to previous standard of normality.

**Comment [S57]:** (Ability to persevere, rest, adjust to community living through difficult times)

**Comment [S58]:** Universality, get visits like others. Having no visitors from family makes one

**Comment [S59]:** Repetition to emphasise the importance of having significant others visit you

**Comment [S60]:** Family visit meet emotional need, recovery more than physical needs

**Comment [S61]:** Fair enough, at the hospital had adequate nutrition, and when we go home

**Comment [S62]:** Tired of eating one and the same food at home, sour porridge, not filling enough

**Comment [S63]:** Tired of eating one and the same food at home, sour porridge, not filling enough

**Comment [S64]:** ?Grandmother really sent her to hospital for this. It's possible, because of lack of

**Comment [S65]:** Hospital admission to get adequate food

**Comment [S66]:** An irony: suddenly talks about her unfair admission to hospital, asserts that she v

**Comment [S67]:** DISCUSS IN NEXT SUPERVISION

Nurses: Reprimand to guide you, as one does to a child (3:85)	R: Who made the false accusation?
Hospitalisation: return to normal, become productive, excel (3:87)	P: It is my mother's uncle. I attended a church service; he is not a Christian himself you see. He is a polygamous man, he then told people that I did not sleep. In the morning I drank my medication, but I confused the medication, then I became very sleepy, I was sleepy. I had put my laundry, then I woke up, I told myself that I needed to buy sunlight, ah! I then saw a car. The people in the car said we want Polile, I only came to look for sunlight and Vaseline, I had to travel to Mbabane. I thought I should buy a few things for my child, and I would go to Mbabane a bit later, I wanted to rest for a bit. I want to stay and attend some services, then go to Mbabane. Awu! They said I am not well I was said to be mad, they told lies about me, stating that I was not sleeping well. They took me to the doctor and told him all this. The doctor did not speak much, all he knows is that this is a patient, she is mad. This is why I am now so fat, yet I was getting ready to go to Nazarene bible college at Siteki where I was going to study as a pastors. This happened three years ago, yes this is the third year. Then they gave me an injection, I was not ill at all. Now this injection makes you feel sleepy, you feel sleepy until it wears off from your body.
Recovery with medication, identify with others, back at work (4:89-91)	R: Please tell me more about the false accusation, that you were not well, while you knew that you were well.
Recovery: perseverance:(4:92)	P: I was very well. I was only excited that I was going to Manzini to refill my medication, that's all. Yet that is a polygamy family. Even though my father had many wives, I did not live amongst a polygamous family, my grandmother brought me up, I only visited my father on a few occasions. But in this area one of the people did not like me, she tortured me and made me to quarrel in this family. I had my house within the home stead, not far from the others. This lady would leave her house to come to mine, and caused trouble; she caused trouble and mocked me. That....at home I lived with my mother before she died, and my two children. We did not have any problem. It was not until one of my half brothers started causing trouble. He smokes weed, he is rude. This weed cause him to be confused, things were not going well, we ended up leaving the homestead. He chased us out of the homestead, stating that we should go out because that was his mother's property. We went and lived with my uncle at Lobamba. When we got there it was war again. Oh no,
Fulfilment of a unique need: visits from significant others and universality (4:97-103)	
Fulfilment of need for visitors emphasised, medication, food not a substitute (4:97-103)	
Home food boring, no variety, self	

**Comment [S68]:** Accused of not sleeping, became sleepy, made a mistake with medication

**Comment [S69]:** Her reasons for being false s to hospital: uncle is not a Christina, a polygamous man, accused of not sleeping, yet she confused her medication, then became sleepy. Stigma – being misunderstood by others, no one want to know me or listen

**Comment [S70]:** Attended church, mother's uncle not a Christian, accused of insomnia, confusing medication, putting laundry, needed sunlight, car come, buying a few things, wanted to go to college? How does weight gain stop one from going to bible college?

**Comment [S71]:** Being in control, having plans, disturbed

**Comment [S72]:** Even though not coming out clearly, seems to indicate lack of involvement by doctor, but knows that patients are 'mad.'

**Comment [S73]:** Professional's assumption, not being listen to by doctor, patients are seen as having less to say, therefore not involved. Medication SE weight gain

**Comment [S74]:** Medication side effects (negative effect on self-esteem)

**Comment [S75]:** Given an injection when not indicated, repetition for emphases.

**Comment [S76]:** Mistreatment, medication side effects (restricted independence), until medication wears out.

**Comment [S77]:** ? Stigma: being misunderstood by others, excitement taken form illness.

**Comment [S78]:** Family/others conflicts, quarrels, possible contribution to illness. Conflict with mother's uncle, and one of the ladies around homestead, half brother came in later on.

**Comment [S79]:** Lady ridicules and mocks

**Comment [S80]:** Half brother's conflict triggered by drug usage

**Comment [S81]:** Left initial residence because of conflicts, chased by half brother.



admission requested (4:105,110)

Voluntary admission for food, makes you better (4:112)

**?Situation/verbal Irony? Flight of ideas? Sudden change of subject** (4:112)

Stigmatised: mentally ill because of different beliefs  
Side effects of medication error, labelled as ill, no one interested in listening (5:118)  
Accused of insomnia (5:125)

Professionals' stigmatisation (5:126, 127)

Injection deprives ones' liberty, becoming unproductive (5:130,131)

we found another war. You know there was this lady at the homestead; she just wanted to fight all the time. You know one day I was sorting my children's clothes; I burnt the ones that were ripped. She started telling everyone, she is mad, she is mad. Even my child, a little boy, I would think that my child had gone to school, but no she would force my child to stay at home and do chores for her. I realized that she did not go to school, and I asked her why she missed school, she told me she was being sent by this lady. This lady would come to my house and insult me, she would insult me and insult me...she would shout on the other side, saying "this mad lady, this mad lady." I was then called a mad person. She does have a brother who is also mad; but he was working at the research centre. I really did not understand this lady; she would provoke me, and provoke me for no reason. I could ask myself "what have I done to this lady to be provoked like this?" she never stopped; she provoked me and provoked me. One day I answered back, I was going to fetch water, she did the same thing, calling me a mad person, this made me so upset, I was also disturbed in my mind, and I had no peace in my spirit. I then left this place; I went to live at Lobamba.

R: Tell me more about what happened when you told the doctor that you were not ill.

P: I did **tell the doctor** *(spoke with a soft voice, with emphases)* **told the doctor** that I was not ill. But they continued to hold me and injected me. **I told them** that I was okay. I was just going to buy a washing soap to do my laundry, this lady told the people that I was not well, and they took me in a car and brought me to hospital. When I came to the hospital, I felt I should phoned my pastor and reported that they took me to hospital even though I was not ill. I felt that what they were doing to me was not right. I phoned the pastor. The pastor came to see me in hospital. They continued to inject me, even though **I told them** that I was not ill, they still gave me the injection. Now this injection has made me gain weight, yet my weight was okay.

R: When did they force you to be admitted in hospital?

P: This was in 2012, my second admission to hospital. I us to suffer from headaches because this lady would talk a lot,

**Comment [S82]:** Being targeted by the lady, no peace within

**Comment [S83]:** Stigmatisation by community

**Comment [S84]:** Lady abused her child, probably taking advantage because her mother is living with mental illness

**Comment [S85]:** Lady would insult Polile: stigma

**Comment [S86]:** Pinkie suffer emotional abuse, called a mad person, this spread to the rest of the community

**Comment [S87]:** Persistent stigma and torture from others, emotional torment leads to being ill, peace within

**Comment [S88]:** Changed voice indicating soft feeling, probably hurting and reliving the experience

**Comment [S89]:** Treatment without consent, has capacity

**Comment [S90]:** Not being listened too. Repetition and emphases of telling people that I was not ill, but one listened

**Comment [S91]:** Lady's rumours had a dramatic negative impact on the participant's life, wrongly sent to hospital, mistreated

**Comment [S92]:** Forced treatment, professionals not listening

**Comment [S93]:** Medication side effects, low self esteem

Misunderstood: excitement or illness (5:134)	and she would insult me a lot. She would provoke me early in the morning, or she could accuse me of doing something I never did. Then I could feel my head aching, it feels like it would split, it was hurting. I started having pains everywhere; I could feel that I was getting hurt through this girl.
Labelled with mental illness because of hatred (5:138)	R: Do I understand you well that you become unwell if or when you have conflicts with others?
Ridiculed and mocked by a neighbour (5:140, 141)	P: Ahaaaa..... hu.....m.....yes, you are not supposed to be provoked by anyone. You must not be tortured or shaken; you must be at peace at all times. For example, I don't work, I don't wake up to go to the boss, I still have my various needs. I have a step mother, she has my money, she does not want to give it to me. I....I...when I have had an injection, I must listen to the injection, I feel like sleeping, you find that you sleep a bit, you sleep a bit, you sleep and sleep a little, instead of resting properly, the step mother does not support you, she tortures you, and does not understand you. Unlike your parents, she also torturers your children, she tortures them. You find that she will take your child, she will take your child and pretend that she loves your child, not that she loves the child, she wants to use your child in her home, her girls sit on beds, you see, her children sleep on the bed, they just roll on the bed, and your child will be working and serving them. They get angry at my children and torturer them. I then stopped my children from going to the step mother. I told the step mother to stop, and I asked her not to touch the child. My life is so difficult now, I have no money, yet my money is being withheld by the step mother. There is not getting up to go to a boss to be, I don't have that strength within me, it is difficult for me.
Half brother causing conflicts, influenced by weed (5:143)	
Chased from home by half brother, lived with uncle (6:145)	R: What have you done about the money that is being held by your step mother?
Conflicts/stigmatised at uncle: sorting and burning old cloths: labelled mad (6:150)	P: There, regarding that, I have asked God's servant, and the church to pray for me. I have been asking from others to help me, asking for offering. They encourage me that I will be better, and they support me with money. When I first came to this place, Lobamba, my body was painful everywhere. I then slept. Concerning money for I go out to town to ask for support. (Moment of silence).
Her children abused by lady, stopped from attending school (6:152)	
Stressful life: being bullied, emotional abuse (6:155-158)	

**Comment [S94]:** Physical symptoms, headache leading to being mentally unstable, talkative lady, insulting Pinkie of stress

**Comment [S95]:** Being emotionally abused leading to presentation of physical symptoms: head ache: splitting pain, hurt, pains everywhere. The emotional abuse from the girl causing hurt.

**Comment [S96]:** Importance of emotional stability, prevents one from being ill

**Comment [S97]:** Although I am not having the stress associated with working, the one I have is not having money. Family conflicts contributing to financial challenges

**Comment [S98]:** Bullied by step mother, refusing to give money from my father's property

**Comment [S99]:** Medication side effects, sleeping a little, not able to work, financial difficulties

**Comment [S100]:** Abused me as well as my children, because she is not my real parent, has no sympathy, pretence to love the child

**Comment [S101]:** Unfair treatment, abused me as well as my children, because she is not my real parent

**Comment [S102]:** Confronted the problem source, protecting the vulnerable, being assertive

**Comment [S103]:** Imposed stress, life made difficult.

**Comment [S104]:** Unemployment

**Comment [S105]:** Lack of inner strength (motivation, will power??). While step mother contributes to financial difficulties, Pinkie seems to be finding it difficult to get the motivation to go to work

**Comment [S106]:** Support from church, through prayer.

**Comment [S107]:** Confidence in the support from others, asking for hand outs, money from others

**Comment [S108]:** Receives financial support from others

**Comment [S109]:** Support from community, town, goes to town to beg for money

<p>Labelled: mad women spreading to the whole neighbourhood (6:156)</p> <p>Continually infuriate, disturbed mind, no peace within: defended herself (6:160-163) Spoke with the doctor, not heard, restrained and injected (6:166-168 )</p> <p>Stigmatised: coerced, mistreated, misinterpreted, misunderstood, misjudged (6:168-170)</p> <p>Mistreated, helpless: fighting back by calling pastor (6:170)</p> <p>Coerced treatment, side effect weight gain (7:174,175)</p>	<p>R: How do you find staying at Lobamba?</p> <p>P: E.....mm, I have been living there for..... this is my second year. We.....ll, we...ll, living there is okay, but I have a problem with the tenants. The tenants are rude. You find that they don't talk well with children, they torturer and intimidate children, they are rude, they are so rude. The tenants are a problem. The princes and princes are okay, they just sit, and they cause no problems.</p> <p>R: Do you live with your children?</p> <p>P: No I don't live with them. They live with their father. They usually visit me during school holiday. It makes me feel good to see them, I am happy when they visit me.</p> <p>R: What makes you feel better at Lobamba where you live?</p> <p>P: It's just a rest, I don't rest much, but the little rest I have makes me feel better. I just sit and rest at the moment, I am useless, but I ask for support so that I can pay rent. I spoke with the prince (who is also the landlord), he was connected with my mother. He is aware of my situation, that my step mother, a Mozambiquean by origin, sold our property at Zakhele, she took the money, we have nowhere to live now, we are stranded. Imagine you have children, you just live.....you now live by God's grace. You just hung up to the cross, I am looking unto the King to fight for me. My father separated with this step mother, he told her to go away, my father chased her. When the house was sold she was the first one to buy it, when the money was supposed to come out she with held it, we are now struggling.</p> <p>R: Is there anything that was done in court about this?</p> <p>P: I did go to the court...at the magistrate....e.hh!! at the master's court. They told me that there was no file. I said let me go to the Provident Fund to check, I found that there was no money. But God helped me there, because that is where they told me where all the accounts books were which my father had. They told me that this booklet is with this one, this is</p>
---	--

**Comment [S110]:** Trouble from others, affected children, other tenants, neighbours are not kind to her children, they are rude.

**Comment [S111]:** Visit from children during school holidays

**Comment [S112]:** Family visit

**Comment [S113]:** Having time out

**Comment [S114]:** Less energy from within (?low self esteem). Seems to acknowledge the fact that she could at least try doing something to generate income, rather than asking from people

**Comment [S115]:** Depends on others for financial support, including paying for her rent

**Comment [S116]:** Hope that God will intervene

**Comment [S117]:** Step mother purchased her husband's house, but did not release the money to the seller



Exasperated by lady's emotional abuse, developed physical symptoms (7:178-180)	with this one, and this was with that other one. My father had three of us from different mothers, I am the only from my mother. My other two half siblings are giving me a problem, they don't make my life pleasant, I am struggling now because of them. The other step mother is a big problem. Even when you are sited in town, you find that their children start <b>gossiping</b> about us, they <b>laugh</b> at us, you can actually see that she is <b>gossiping</b> about you to her friend. She <b>gossips</b> and <b>gossips</b> and <b>gossips</b> , even the <b>insults</b> , they <b>insult</b> you. They are bad, really bad. Even when she passes next to you. You feel a lot of pain, she has spirits that this girl spread to you, she spreads some of them to you. The other one, you find that you are sat next to her, you will feel a sharp pain pricking you on the chest ( <i>she pointed to her chest where the pain is felt</i> ). My child also, once I was her, and she told me mum I am dying on the chest. Then, God had showed me that this lady is evil, she put something here ( <i>pointed to her chest</i> ).
Recovery associated with emotionally stable (7:186)	R: How are you coping with this situation?
Not employed advantageous, less stress, can sleep, misunderstood by step mother (7:187)	P: Hayi!!! It is bad, the situation is bad. It is so bad, just like now, I have been called to marriage, it is so very bad now.
Step mother: not supportive responsible for financial abuse (7:188)	R: Please explain what you mean when you say you are called to marriage.
Step-mother tortured me and abused my children (7:191-197)	P: I me.....an. I me.....an God has given me the gift of marriage and preaching. This means that I have to get married, and preach. I need money for my wedding; the money is not coming out! There is so much conflict now, they don't agree, they are now insulting me, they insult me, they torture my children. We are always fighting with my half siblings. You are preparing for a wedding, people fight. It is difficult. Because this demon was moving around, causing confusion everywhere. What was happening there would happen there, it would happen there, here and there, and there, just like that. It is so locked now, it is only grace.
Financial difficult, step mother's financial abuse a contribution (7:199-200)	R: What does your partner say about this?
No strength/	P: That you are given by God. God will give me. He is not here yet, but God will give me when the time comes. God is still preparing me, so that I will be ready when the time comes. God is still sorting this money issue where Satan had

**Comment [S118]:** Perpetual distress as a result of family conflicts, surrounding finances. Could be better of looking for alternative means of generating income, rather than depend on the money that she might not even get. Also, it's release is likely to bring temporal relieve, what will happen when it is all used up.

**Comment [S119]:** Stigmatisation: insults, mockery of by step mother's children, causing friction and discomfort, even when in the community. Repetition of 'gossips, insults.'

**Comment [S120]:** Non invisible torture

**Comment [S121]:** God's help. Felt reassured and comforted by insight into the lady's heart, shared by God.

**Comment [S122]:** Going through difficult times

**Comment [S123]:** Financial constraint, restricting social progress. Does not seem to have an alternative to what she says is important to her

**Comment [S124]:** Repetition appears to be more of a defence mechanism or maybe a self pity. Appears needy, probably used to asking for support from people around, as she says.

**Comment [S125]:** Family conflict hinder progress. Use of a metaphor 'locked' to mean the intensity of the problem. Does not seem to have a solution or a suggested way forward.

<p>motivation to work contribute to financial difficult (7:201,202 )</p> <p>Spirituality: trust in the supernatural to help (8:203)</p> <p>Finical support received through offering from others (8:205, 208)</p> <p>The pain of seeing one's children being abused (8:213,214 )</p> <p>Rest not helpful, appears to feel worthless, not industrious/ energetic (8:223)</p> <p>Step mother: financial abuser, non empathetic (8:226-228)</p> <p>Surrendered problems to God: (8:229)</p> <p>Looked for solution, prove fruitless, files</p>	<p>blocked me, because there is nothing impossible with Him. You just need to focus on him. He will open away, he is faithful to do this, you have to be quiet and wait, and do whatever her wants you to do.</p> <p>R: From what I gather, you seem to benefit from your religious values.</p> <p>P: Oh yes! I get a lot of help through God. You know, just like me, I get a lot of help at church. You mean, just like me, I don't wake up at the moment, but I get a lot of support from the church, like the church I go to, at pastor Janu. You don't have uniforms you have a child, just like me, you can get your child's uniform, you get that sort of help. You just abide with the King; God helps you and meet you at your point of need. You find people helping you; you only have to hold on to him.</p> <p>R: Thanks a lot for sharing with me such sensitive issues. You appear to be positive women, with determination to succeed, which is good.</p> <p>P: Yes if you trust God, he open for your big opportunities, it is amazing to rely on him. This is what keeps me going.</p> <p>R: What are some of the things that you think could be done either at home or in the hospital that could promote your recovery from the illness of the brain?</p> <p>P: Eh!.....Eh.....I am looking at this thing that happened to me, it really hurt me (<i>her voice became loud</i>). That I was given an injection when I was well, I was not ill. This injection hurts your life, you find yourself being dragged on the floor. That I was given an injection when I was not ill, this has really hurt me. All along I had no problem, but now I was given this injection, this hurt me.</p> <p>R: Do you still get the injection?</p> <p>P: No, it was only for that time.</p>
---	--

**Comment [S126]:** Expression of home through trust in God to sort things out.

**Comment [S127]:** Hope that things will get better through supernatural intervention. Trusts God for help.

**Comment [S128]:** Community help, church support, by trusting in God

**Comment [S129]:** Continuous belief and trust in God makes others want to help, no other thought of intervention, but would rather continue to trust God

**Comment [S130]:** Trust in God gives hope for better things coming

**Comment [S131]:** Emphases on bad experience being injected when she did not need it.

**Comment [S132]:** Hurt by being mistreated, wrong diagnosis. Felt like being dragged on the floor. Possible being trampled upon, useless, treated without respect. *Feeling of pain, irreversible hurt in her change of voice, louder, and her repetition of the experience, along with her use of words to emphasis, 'really hurt, dragged on the floor..'*

**Comment [S133]:** S.E. lead to regression

**Comment [S134]:** Professional wrong diagnosis, introduction on problem, one which is long term and permanent

missing in court (9:238)	R: Thank you for mentioning this. It was my concern as well. From what I gather you feel like nobody listen to you.
Trust God's intervention (9:236)	P: Oh yes, this really hurt me, it hurt me a lot.
Conflicts with half siblings (9:240)	R: What have you done about this or what would you like to do about it?
Ridiculed, mocked & insulted by siblings (9:242-246)	P: Well I didn't do anything. I did tell the nurse who was giving me an injection that I was not ill. But because I was talking to much trying to defend myself, I think she said, she is shouting, she is ill indeed, she needs the injection. Yet I did not need the injection. The only problem I had was at home, yet because I believe in God, I do pray, he helps you when you are in need. Just like where I live now, there problems are there, there is a lot of noise at times, but God helps me and removes the things that cause trouble. But the injection just kills you. You know I use to come to the hospital and tell them that I am not okay, I am not okay, I am hungry, and they gave me food and I went back home. This injection made me to swell, I became fat. I don't take that injection any more, I just take the tablets, what is it, Oh! I take olanzapine and artane. These are good, I am happy with my medication. The only thing is that I do feel tire, and I think I will sleep when I get home, I feel sleepy.
Evil from half siblings is contagious, physical effects (9:246-249 )	R: What would you like to be done about this issue of being given an injection when you we not ill?
Coping strategies: reassured by God's revelation about the lady (9:251)	P: I want the staff at the hospital to listen to patients, not to just inject them without listening. You know I met a pastor when I was admitted here, he was in seclusion. I was shocked that he was here, he said to me hey! I was stood at the bus rank, holding my bible, the police came to me, they said, we are told by this person that you are not okay, you are mad, you are not well, get in here. He said this is how I am here. The pastor said he does not wish this to happen to anyone else, and even to happen to him again. This is my wish as well, that this will never happen again. That I will be given an injection when I a not sick, I felt that I was not sick, because I know myself. I know my illness. I know the importance of taking my medication, and I don't want to died because I have my children. So I don't know why they forced me to get that injection. I take my medication properly. This injection wasted my time because it made me feel like I was being
Difficult circumstance: (9:256-286 )	
Retarded progress: bible college and marriage: no money (9:256, 257)	
Perpetual family	

**Comment [S135]:** Emphases how hurt she was following the incident of being treated earlier than desired.

**Comment [S136]:** Professionals: Miss diagnoses, not being listened to, talked to the nurse but was not listening.

**Comment [S137]:** Professionals: assumption, and misjudgement. Shouting for help, she says she was defending herself, misunderstood of being unwell.

**Comment [S138]:** Religious believe

**Comment [S139]:** Continuous referral to the mistreatment received in the past. Distress from mistreatment. Preoccupied with traumatic experience, observed desire to talk about this, and possibly have it rectified.

**Comment [S140]:** In the past, approached staff to ask for food, and they gave it. This sentence is introduced in the middle of her conversation about her bad experience, possibly trying to understand why staff did not listen to her this time, as they had done in the past when she had come to ask for food. But why did they not recognise me and or listen to me this time when I was forcefully brought to hospital again.

**Comment [S141]:** SE from medication

**Comment [S142]:** Professionals must listen to clients

**Comment [S143]:** During admission, also mentioned others who said they were unfairly admitted

**Comment [S144]:** Others not to go through the same bad experience

**Comment [S145]:** Desire to comply with treatment, something worth living for

<p>conflicts, no progress (9:258; 10:260-264)</p> <p>Trust in God brings home, coping strategy, helps to persevere (10:267-269)</p> <p>Hopes that things will be sorted at the right time (10:270,271)</p> <p>Have confidence in God and church due to previous provision (10:275-279)</p> <p>Strongly belief in God for future success (10:282)</p> <p>A desire for change: reiterated back treatment when not ill (10:287-288)</p> <p>Chemical restrained: injected (10:288)</p>	<p>dragged on the floor. I felt like I was locked in, yet life was moving, this was a waste of time.</p> <p>R: Even though I will not mention your name, I will inform the management of the hospital about the experience you went through, and will inform them that your want staff to listen to patients and discuss the best alternative treatment, rather than to impose treatment to them. Thanks a lot for you time. Do you have any questions or anything else you would like to tell me?</p> <p>P: No I don't have any questions. In the past though they said we should bring our PIN number so that they could give us money every month. We did this but it did not succeed, we did not get the money (<i>she laughed</i>). They told us money was coming, we were very happy, but no money came. They promised to give us money, we never got any.</p> <p>R: I am not sure about that. Maybe the nurses at the OPD might know if you ask.</p> <p>P: Ah!! I would ask another time when I return for my month refill.</p> <p>R: Thanks very much for your time.</p> <p><b>Reflection:</b></p> <ul style="list-style-type: none"> <li>• This participant encouraged me because she was open and chatty about her story.</li> <li>• She presented as a strong believer in God, and seemed to receive comfort and encouragement from her belief and the church</li> <li>• At one point I felt angry about the step mother who took the money from the sale of the property, and the fact that the documents were missing at the magistrate court. I felt sorry for this lady</li> <li>• I wondered what happened to the initiation of ? benefits for patient living with mental illness. I would like to explore this further, at a later date.</li> </ul>
--	--

**Comment [S146]:** Mistreatment retards progress, low esteem

**Comment [S147]:** Financial support did not g through

<p>Irreversible effects: dragged on the floor, life time pain, was normal before (11:289)</p> <p>Talked to nurse, not heard (11:298)</p> <p>Self defence, being assertive, labelled as abnormal behaviour (11:299)</p> <p>Trust in God for help (11:302)</p> <p>Coerced treatment: the pain that never dies (11:304)</p> <p>Staff listened to me in the past when I had come to ask for food. Why did they not listen to me this time (11:305, 306)</p> <p>OR</p>	<ul style="list-style-type: none"> <li>• I some time questioned Pinkie's wellness when taken to hospital by force. She seems to have a lot of flight of ideas, and there is a lot of incoherence and contradiction in her narration.</li> </ul> <p>Reflection: Researcher being judgemental Not a clear narration, presents like one with flight of ideas, with some incoherence: (5:118-125)</p> <p>Reflection: There is a discrepancy in her story, initially told of going to church, and to Mbabane, now she was going to Manzini to refill her medication? (5:124-138)</p> <p>OR she means</p> <p>Do they not recognise that I am the same lady who use to ask for food and went back home (11:305, 306)</p> <p>Body disfigured by injection, loss of self confidence, esteem (11:307)</p> <p>A plea for staff to pause and listen to patients at all times (11:313)</p> <p>Found others in hospital who were wrongly admitted: pastor (11:314-316)</p> <p>A wish that other would not go through the same experience, its damaging (12:318, 319)</p> <p>Injection a hindrance: physically, emotional and life progress (12:324,325)</p> <p>Promised financial support at the hospital, did not materialise (12:334-336)</p>
---	---



